S. HRG. 100-872

ADULT DAY HEALTH CARE: A VITAL COMPONENT OF LONG-TERM CARE

HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

SECOND SESSION

WASHINGTON, DC

APRIL 18, 1988

Serial No. 100-20

S141-3

Printed for the use of the Special Committee on Aging

U.S. GOVERNMENT PRINTING OFFICE

87-615 WASHINGTON : 1988

For sale by the Superintendent of Documents, U.S. Government Printing Office
Washington, DC 20402

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ADULT DAY HEALTH CARE: A VITAL COMPONENT OF LONG-TERM CARE

MONDAY, APRIL 18, 1988

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The committee met, pursuant to notice, at 9:35 a.m., in room 628, Dirksen Senate Office Building, Hon. John Melcher (chairman of the committee) presiding.

Present: Senators Melcher, Bradley, Burdick, Shelby, Grassley, Domenici, and Chafee.

Staff present: Max Richtman, staff director; Natalie Cannon, professional staff; Dianna Porter, professional staff; Bill Ritz, communications director; and Kelli Pronovost, hearing clerk.

OPENING STATEMENT BY SENATOR JOHN MELCHER

The CHAIRMAN. The committee will come to order.

This morning's hearing is on a partial answer to what I believe is everyone's question, and that question is, if older Americans are to be able to stay in their homes and enjoy their homes and regular community life, what can we do or what is being done to make that possible, providing they need health care? And many older Americans, as we know, all need some health care at home.

In fact, HHS tells us that there are between 4.5 million and 5 million older Americans who are at home and, for one reason or another, have to have some assistance regarding health care.

Now, it is obvious, I think, to everybody why people want to stay in their homes. It is the continuity of family life, the continuity of being part of the community—much more so than being in a nursing home. So, that is what families and individual older Americans strive to do.

Now, if we were going to start on the premise of just economics, I guess we would say, well, does this save money? And the answer to that is emphatically yes, it does save money.

And for whom does it save money? It saves money for the families, and it saves money for Medicare, and it saves money for Medicaid. So, both the individual and their families save money, but, also, the government saves money.

So, what is being done in this regard? Well, not enough, we find out, but one of the bright spots is that there are adult day care centers throughout the country. I am told there are over 1,400 adult day care centers, which is a place where an older American or a handicapped individual, regardless of age, can come and get a

degree of care related to health and related to making life interesting.

So, some families with an adult elderly person can actually bring the person there or there is a bus that goes out or a car goes out and picks up the person or a van goes out in the case of a wheelchair and picks up the person, and they come and spend part of the day or perhaps all day in this adult day care center.

Two-thirds of the elderly who are needing some help—sometimes we call them frail—or are disabled live with their families right now. So, in many instances, it is a case of are the family members who work able to work and to be gone from the home. And who takes care of the elderly person or the disabled adult? This is a partial answer, adult day care centers.

What is the cost? Nationally, I am told that the average cost per day is $31. Now, we have to measure that against, for instance, a stay in the hospital which is a great deal more. Sometimes, this relieves the need for somebody who needs some care of having to spend extra time in the hospital. Also, obviously, $31 a day is a pretty good figure to look at in terms of what it costs to be in a nursing home which is between $60 and $70 a day.

So, adult day care centers are performing a very useful need, and they are a bright spot in how we provide for an older American who needs some health care at home, how we keep them at home and, therefore, better satisfied and save some money for both the family and the government.

Right now, adult day care programs are funded with a patchwork of funding. Maybe we can't relieve that, but there are a number of us here in the Senate, myself included, who believe that this fits into Medicare. So, we are seeking ways to do that.

Naturally, if there is another financial drain on Medicare, we have to come up with the funding for it. We recognize that, and we are looking at the means of possible funding by adding this as a part of Medicare's responsibilities and obligations.

[The prepared statement of Senator Melcher follows:]

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United States Senate
SPECIAL COMMITTEE ON AGING
WASHINGTON, DC 20510-6400

OPENING STATEMENT

SENATOR JOHN MELCHER
CHAIRMAN, SENATE SPECIAL COMMITTEE ON AGING

April 18, 1988
ADULT DAY HEALTH CARE: A VITAL COMPONENT OF LONG TERM CARE

Good Morning. I welcome everyone to this morning's hearing by the Senate Special Committee on Aging on adult day health care and its role as a vital component of long-term care.

Adult day health care is a relatively new long-term care service. As a result, it only recently has begun to receive the recognition it deserves as an option in the continuum of care.

As Congress begins serious consideration of legislation for long-term care, I feel that it is important for us to learn more about adult day health care programs around the country. How do they assist frail elderly and disabled adult participants and their family caregivers? How effective are their services in saving costs and delaying or preventing our elderly from having to enter a nursing home?

More than 1,400 adult day care programs are now in operation throughout the United States, serving more than 66,000 persons a day. Most of these programs have grown rapidly at the grassroots level over the past 10 years. They offer a comprehensive range of services, usually under the supervision of a multidisciplinary team of professionals. These include health assessment and monitoring, personal care, a hot meal, counseling, therapeutic recreation, transportation, and -- quite often -- physical, speech, and/or occupational therapy.

However, adult day care programs, for the most part, lack a stable base of funding. Most are financed by a patchwork of public and private funds, philanthropic donations and private client fees. The federal share of funding sources is: Medicaid, 14 percent; Social Services Block Grant, 12 percent and Administration on Aging Title III, 6 percent. The national average cost of a day of adult day health care is about $31.

About 65 percent of the frail elderly and disabled adults who participate in adult day health centers live with family caregivers or friends. The almost constant, unpaid care given by families and friends is usually the critical factor in preventing or delaying their entry into nursing homes.

But if adult day care is important to keep frail and disabled adults in their communities and out of institutions, adult day care is absolutely crucial to family caregivers and friends. Understandably, the life of a caregiver is fraught with stress. To a caregiver who also must hold down an outside job, the stress is almost impossible. For them, adult day health care means they can continue their jobs or go to the grocery store or even take a few hours off for some solitude in the library. For these people, adult day health care is a must.

Because I know that adult day health programs offer not only professional but compassionate, individualized and cost-effective care, I firmly believe we must make it a high priority as an integral part of long term care.

I would like to commend some of our witnesses here today, as well as others in the audience, for their commitment and dedication in the adult day health field. They are the ones that help make the difference in assisting our impaired elderly to live independently in their communities as long as possible.

I am looking forward to hearing from today's witnesses who will tell us more about adult day health care, its benefits, effectiveness and the need for its services.

Our first witness today will be George and Jean Glakas. George, who had a stroke six years ago, now attends the adult day health center in Annandale, Virginia. His wife, Jean, carries on the family business, which she could not do without day health care for her husband.

Our next witness is Lou Glasse, president of the Older Womens' League, who will testify about the role and stress of family caregivers and their need for support.

Then we will hear from Don Peterson, administrator of St. John's Nursing Home in Billings, Montana which also has an adult day care program. He also represents the American Association of Homes for the Aging which operates adult day care programs in about 320 of their facilities.

Kay Larmer will testify next as coordinator of adult day health programs in Fairfax County, Virginia and also as chairperson of the National Institute of Adult Daycare, an organization of professional persons who work in this field.

In addition, we'll hear from Ellen Shillinglaw, who will speak on behalf of the Health Care Financing Administration as Director of the Office of Legislation and Policy.

Our final witness will be Carol Kurland, Administrator of the Office of Home Care Programs for the state of New Jersey. She will describe how their effective Medicaid-funded program works as well as its benefits to participants and caregivers.

We have an interesting morning ahead of us so I suggest that we begin.

The CHAIRMAN. To begin this morning's hearings, we are going to watch a videotape. Gretchen Meinke who is Administrative Director of the Adult Day Health Network of United Way of San Francisco will be introducing the tape.

Gretchen, we would like to have you do that right now.

STATEMENT OF GRETCHEN MEINKE, ADMINISTRATIVE DIRECTOR, SAN FRANCISCO ADULT DAY HEALTH NETWORK, UNITED WAY

Ms. MEINKE. Thank you very much.

Senator Melcher, as you are aware, long-term care of the frail and chronically ill elderly is one of the major issues facing our nation today, and I would like to commend you for your efforts in working on this important issue.

Adult Day Health is one important community based long-term care option, and the program provides health, social, and rehabilitative services for frail elders and disabled adults in a community center. The program also provides important support and respite for care givers, as the videos that we are going to see today will show.

San Francisco has a city-wide network of centers, and, together, they provide health, social, and rehabilitative services to over 1,200 frail elderly individuals and disabled adults.

The films that you are going to see now include a portion of two spots. The first was prepared by KGO–TV and aired on the nightly news. It depicts St. Mary's Adult Day Health program which is a hospital-based program in San Francisco.

The second was prepared by United Way as part of their annual campaign and emphasizes support for the care giver.

Both highlight the value of Adult Day Health in San Francisco, and I am pleased to have a chance to show them to you.

[The showing of video tapes proceeded.]

[Transcripts of video tapes follow:]

TRANSCRIPT OF VIDEO ON ADULT DAY HEALTH CARE

Channel 7 News, (ABC) KGO TV, San Francisco (11/6/86)

Anchor: "Help is available for elderly people who don't want to go in a nursing home but may be unable to take care of themselves in their own homes. Channel 7's Ed Baxter reports on a possible solution being tried now in San Francisco."

Reporter: "78-year-old Odessa Curie would be in a nursing home if it weren't for St. Mary's Adult Care Center and for the strong will of her son, Harold."

Harold: "I'm the only child she has and I see many children that use the hospitals and convalescent homes as a dumping ground; I'm going to stay with her until I just can't do any more. I couldn't thank my mother for the times that she had to get up at night, or take me to the doctor; when I hurt myself she'd wrap up the wound and so forth."

Odessa Curie: "I'm proud of him."

Reporter: "Our society is growing older; census bureau figures show by the year 2000 the over-75 age group will be the second fastest growing. This center, St. Mary's, is part of a network of seven in San Francisco, and is being used as a model for other parts of the country as a way to let our elders stay in a home environment rather than having to go to a nursing home full time."

John Daw, Director of St. Mary's Adult Day Health Center: "Primarily they are here to receive skilled services: nursing, physical therapy, occupational therapy, speech therapy, social services, and recreational services. That also gives the families respite which is very important when they have 24 hour responsibility for a frail elderly person."

Reporter: "So it helps working couples the same way child care centers do at the other end of the age spectrum. People who run the centers say that it is a lot less costly than full time nursing care. Their fee schedule is based on a sliding scale and subsidized by charity and private sector organizations. For Odessa, it means no nursing home."

In San Francisco, Ed Baxter, Channel 7 News.

United Way Spot:

Narrator: "For many people the problems of general aging are fulfilled only through the help and support offered by United Way funded agencies. Growing old for some brings frailty and the need for special care and nurturing. Many are stricken with Alzheimers disease, a condition that is debilitating not just for the person who is affected, but for the family as well. One program that is making a difference is the San Francisco Adult Day Health Network."

Mrs. Edith Fried: "My husband was a newspaper critic for over 50 years, a music critic and arts critic for first the Chronicle and later on for the San Francisco Examiner and he loved his work. And the strange thing now is that he never even listens to music; there is nothing of the intellectual ability left in him. I would never send him, as long as he has any feeling of being a person himself; I would never send him to an institution where he is taken care of day and night. I would not completely detach myself from the care, so I think this day care center is just the right thing for both of us. The center has given back to me a few hours every day at least four times a week now, a few hours that I can call my own and act as a normal healthy person. As a caregiver, you have the feeling that you are taking care of somebody who is very dear to you, almost like taking care of a child, but you have the frustration of trying to take care of someone who is gradually deteriorating. One day he can do something and the next day he can't do it anymore. He likes it very much and every morning he is looking forward to going. These people are doing the greatest charitable act that I can think of and I am deeply grateful to them. They have infinite patience and are forever friendly, cheerful, and uplifting and all of them are that way. I don't think I could have lasted as long as I have, now almost the 10th year, if I hadn't discovered the center for the last two years. This has given back part of life for me that I think everyone is entitled to."

The CHAIRMAN. The committee will be in recess for two or three minutes while we remove this equipment.

[Recess taken.]

The CHAIRMAN. The committee will come to order.

Ms. Meinke, thank you very much for these very informative video tapes. I believe seeing is believing, and through your video tapes, we have been able to see and believe, see what can be done, what is being done in San Francisco, and believe that it is the right thing to do and should be broader to reach every family with an older American or a disabled American who, ideally, would have access to such day care centers as you have portrayed in your video tape.

Senator Shelby.

STATEMENT BY SENATOR RICHARD SHELBY

Senator SHELBY. Thank you, Mr. Chairman.

I want to again express my appreciation to you for calling this hearing. Adult day health care, I believe, is a sensible approach to meeting the needs of our adult citizenry, and it is an important step in addressing the problem of providing long-term care.

Your leadership on this subject, Mr. Chairman, is truly commendable. I was proud to co-sponsor your bill, S. 1839, the Medicare Adult Day Health Care Amendments of 1987, and would encourage my colleagues to support this vital legislation.

Much attention has been focused recently on the need to ensure that every American has access to our health care system. Unfortunately, many individuals are barred from receiving medical attention due to their inability to pay and lack of adequate insurance coverage.

Currently, we are waiting for Congress to take final action on important steps toward expanding Medicare coverage. Last year, as we all know, the Senate passed S. 1127 which would allow Medicare to pay a portion of the costs of catastrophic acute care. We must continue our efforts along these lines.

Throughout the debate on the catastrophic bill, we heard of the even more serious dilemma of how to finance long-term care. The elderly segment of our population is growing more rapidly than any other group. As our population continues to age and the baby boom generation matures, the need for an effective means of providing coverage for the costs of long-term care will be increasingly imminent. Adult day health care is a common sense approach to meeting this challenge.

An adult day health care center provides the maximum benefit to participants, families, and the community. We all recognize the importance of maintaining our independence. Adult day health care facilities offer impaired adults medical and social support-related services, thereby preventing or delaying placement in nursing homes. This affords individuals the opportunity to stay with their families in their communities.

Many of the primary care givers of elderly individuals are family members. These care givers are usually working adult children who must frequently quit work or reduce the number of working hours to care for their aging relatives. And regardless of this effort,

most relatives are not medically qualified to provide the type of care needed by elderly relatives who are often afflicted with such ailments as Alzheimers disease, stroke, head injuries, or other physical or mental impairments.

Most adult day health care centers are staffed with trained professionals who are qualified to provide medical care, speech or physical therapy, or whatever the individual need may be. Such assistance is given in accordance with an individual plan of care in a protective group setting.

But these centers offer participants more than health-related care. Adult day health care facilities are centers of socialization as well.

With increased interaction with family, friends, and peers, an individual is able to assert a higher degree of independence than if he or she were confined to a nursing home.

In these days of budgetary restraint, it is rare when a solution presents itself as both humane and cost effective. However, adult day health care can prevent or delay institutionalization of elderly adults in nursing homes and can allow participants to remain in their homes and communities. This ultimately saves dollars, for the cost of care provided in an adult day health care center is usually far below the price tag attached to nursing home care.

Long-term care is a challenge we must face today. Adult day health care is an important step in addressing the needs of our elderly population.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator.

Senator Chafee.

STATEMENT BY SENATOR JOHN CHAFEE

Senator CHAFEE. Thank you, Mr. Chairman.

First, I want to thank you for holding this hearing on adult day health care, and I want to commend your efforts in examining possible solutions to this multi-faceted problem of long-term care.

We are all keenly aware of the difficulties the elderly face in paying for long-term care. It is critical, I believe, that we find a practical and financially sound solution so that elderly and disabled individuals have both high quality and appropriate long-term care services. I believe that adult day care must be a significant part of any solution.

One of our most important assets we have in our country is the family. I believe we should do everything possible to ensure that families can remain together as long as possible.

Unfortunately, and this is absolutely true of the Federal policies currently, they represent an all or nothing proposition. To obtain long-term care assistance today, an individual must spend all of his or her assets and go into a nursing home or institutional setting before Medicaid will help. We do nothing to give families assistance such as day care or respite care to support their efforts to keep a parent or other loved one at home.

It is for this reason that I am pleased to report that I have joined as a co-sponsor of the Medicare Adult Day Health Care Amendments of 1987, S. 1839. This legislation would provide additional

funding for the adult day care centers for people so desperately needing them.

In addition, this bill will provide respite care for families who wish to help their elderly relatives remain at home.

So, I am glad to support this effort, Mr. Chairman, and I look forward to educational and insightful hearings today.

Thank you.

Unfortunately, I, like so many of us, have another conflict at 10:30, but I will stay as long as I can and will review the record afterwards.

The CHAIRMAN. Thank you, Senator.

Senator Grassley.

STATEMENT BY SENATOR CHARLES GRASSLEY

Senator GRASSLEY. Mr. Chairman, I also have HUD and Independent Agencies Appropriations Subcommittee at 10:30, but I am going to stay here until that period of time.

I thank you for holding your hearing this morning. It is going to provide some very useful testimony on the value of adult care services.

Of course, I don't think very many people need to be convinced of the importance of adult day care, because it can help avoid institutional placement of individuals, and it is also going to keep the family involved in care of people which is good for the family and is also less expensive.

We now have, as is so often and truly noted, very much an institutional bias in our long-term care non-system, an institutional bias supported and held in place by our financing mechanisms for long-term care. I think it is obvious that we need a better balance in the available services as between institutional care and care in the communities such as adult care and home health care.

The only notes of reservation that I have to raise, Mr. Chairman, with respect to the proposals for the new initiatives for long-term care such as for the adult day care program under Medicare on which you have shown such leadership, have nothing whatsoever to do with the benefits of adult day care services in relationship to the outstanding needs or relationship to other services currently more readily available such as nursing home care.

We have had many bills introduced. Of course, this hearing is going to help us know whether Senator Pepper's proposal or Senator Kennedy's or yours or whether a combination of those is the best. However, as you know, I have been a supporter over the years of programs for older Americans, and I think I am as aware as anybody of the truly vicious nature of our long-term care non-system.

Yet, as this debate heats up—and it is going to be a major part of the presidential campaign as I see each of the candidates today as well as the original 13 candidates addressing the subject of long-term care—the pressure on Congress grows from the community of people interested in getting at long last some kind of a major start in solving this problem.

I don't think we can afford to lose sight of the first question I raised, and that is how it is going to be paid for. Presently, we are

running a deficit of $150 billion. We are certainly aware, those of us in this body, at any rate, of just how difficult it has been to make even as much progress as we have made in the last couple of years on the deficit problem.

Furthermore, we all know very well how much difficulty we are having just in meeting current obligations under the Medicare program. I remind all my colleagues, as well as I have to remind myself from time to time, that we still anticipate very serious difficulties in keeping the hospital insurance trust fund in a solvent state, although we have managed so far to keep pushing off the day when it runs out of money. That has been pushed off about 7 or 8 years just in the actions we have taken in the last 2 years.

With respect to long-term care, according to a recent paper by the Congressional Budget Office, Federal expenditures are expected to almost triple by the year 2000 from $14 billion to $45 billion in constant 1985 dollars. The astonishing thing about the estimate is that it is based just on current law.

It doesn't take into consideration the acute care catastrophic legislation presently in conference or any other long-term care proposals which have been introduced in the Congress.

Note also that the estimate is only for the period up to the year 2000. We know that the baby boom doesn't begin to retire until the year 2009.

This whole deficit problem is compounded by the great growth we are anticipating in the Social Security trust fund. Essentially, these surpluses make the current deficit seem smaller than it really is.

In 1993, the Social Security surplus is anticipated to be around $100 million. This is the year, of course, when the budget deficit reductions under Gramm-Rudman are supposed to get us to a zero deficit.

Unfortunately, the Social Security trust funds, as required under Gramm-Rudman, will no longer be counted in reckoning the deficit after that year. Hence, when we are done with Gramm-Rudman, we are going to find ourselves still facing a deficit which is enormous by historical standards.

So, the whole matter of the Social Security trust funds, of course, is more complicated than simply counting it or not counting it, but that is not my purpose here. The main point that I am trying to make, Mr. Chairman, is that we need to be very careful before starting up any new long-term care problem, whether it be your proposal, Mr. Chairman, or more comprehensive long-term care programs as we are now being urged to do by so many voices, particularly by those people campaigning for President.

The reason for this is that one day this country is going to have to deal with the retirement of the baby boom generation, and it is not clear just how we are going to provide them with the benefits we currently promise to provide older people to say nothing of providing them with yet new benefits like we are proposing here, and that doesn't detract from the fact that I know, Mr. Chairman, that when you have adult day care and keep people out of nursing homes, that is saving money in the long run.

Mr. Chairman, thank you.

[The prepared statement of Senator Grassley follows:]

Chuck Grassley

STATEMENT OF SENATOR CHARLES E. GRASSLEY FOR A HEARING OF THE SPECIAL COMMITTEE ON AGING ON ADULT DAY CARE, MONDAY, APRIL 18, 1988

THANK YOU, MR. CHAIRMAN.

I THINK YOUR HEARING TODAY WILL PROVIDE USEFUL NEW TESTIMONY ON THE VALUE OF ADULT DAY CARE SERVICES. MANY OF US, OF COURSE, HAVE BEEN CONVINCED FOR SOME TIME OF THE IMPORTANCE OF ADULT DAY CARE. IT DOES SEEM TO ME THAT ADULT DAY CARE CAN HELP TO AVOID INSTITUTIONAL PLACEMENT OF INDIVIDUALS WHO MAY BE AT SOME RISK OF SUCH PLACEMENT. IT PROBABLY CAN ALSO HELP KEEP FAMILIES IN THE WORK OF TAKING CARE OF DEPENDENT OLDER RELATIVES, WHICH IS SURELY A VERY, VERY DESIREABLE GOAL. GOAL.

WE NOW HAVE, AS IS SO OFTEN AND TRULY NOTED, AN INSTITUTIONAL BIAS IN OUR LONG TERM CARE "NON-SYSTEM", AN INSTITUTIONAL BIAS SUPPORTED AND HELD IN PLACE BY OUR FINANCING MECHANISMS FOR LONG TERM CARE. I THINK IT IS OBVIOUS WE NEED A BETTER BALANCE IN AVAILABLE SERVICES AS BETWEEN INSTITUTIONAL CARE AND CARE IN THE COMMUNITY SUCH AS ADULT DAY CARE AND HOME HEALTH CARE.

THE ONLY NOTES OF RESERVATION I HAVE TO RAISE, MR. CHAIRMAN, WITH RESPECT TO PROPOSALS FOR NEW INITIATIVES IN LONG TERM CARE --- SUCH AS FOR A NEW ADULT DAY CARE PROGRAM UNDER MEDICARE ON WHICH YOU HAVE SHOWN SUCH GREAT LEADERSHIP ----- HAVE NOTHING WHATSOEVER TO DO WITH THE BENEFIT OF ADULT DAY CARE SERVICES IN RELATION TO OUTSTANDING NEEDS OR IN RELATION TO OTHER SERVICES CURRENTLY MORE READILY AVAILABLE, SUCH AS NURSING HOME CARE.

THEY HAVE TO DO WITH HOW WE ARE GOING TO PAY FOR ANY NEW FEDERALLY FINANCED SERVICE PROGRAM, AND WHICH AMONG THE VARIOUS PROPOSALS BEFORE US -------- SENATOR PEPPER HAS A HOME CARE BILL WHICH WILL BE VOTED ON IN THE HOUSE EARLY NEXT MONTH, SENATOR MITCHELL WILL INTRODUCE A MAJOR LONG TERM CARE BILL LATER THIS MONTH, SENATOR KENNEDY HAS PROMISED A MAJOR NEW LONG TERM CARE PROPOSAL, AND, AS YOU KNOW, NUMEROUS OTHER LEGISLATIVE PROPOSALS HAVE BEEN INTRODUCED ------- OFFERS THE BEST WAY TO PROCEED ON THIS LONG TERM CARE PROBLEM.

AS YOU KNOW, I HAVE BEEN A SUPPORTER OVER THE YEARS OF PROGRAMS FOR OLDER AMERICANS. AND I THINK I AM AS AWARE AS ANYONE OF THE TRULY VICIOUS NATURE OF OUR LONG TERM CARE "NON-SYSTEM".

AND YET, AS THE DEBATE HEATS UP ON THIS ISSUE AND THE PRESSURE ON THE CONGRESS GROWS FROM THE COMMUNITIES OF PEOPLE INTERESTED IN GETTING, AT LONG LAST, SOME KIND OF MAJOR START ON SOLVING THIS PROBLEM, WE CAN'T AFFORD TO LOSE SIGHT OF THE FIRST QUESTION I RAISED - - - - - NAMELY, HOW ARE WE GOING TO PAY FOR IT?

PRESENTLY, WE ARE RUNNING A DEFICIT OF AROUND 150 BILLION DOLLARS. AND WE ARE CERTAINLY AWARE, THOSE OF US IN THIS BODY, AT ANY RATE, JUST HOW DIFFICULT IT HAS BEEN TO MAKE EVEN AS MUCH PROGRESS AS WE HAVE MADE IN THE LAST COUPLE OF YEARS ON THE DEFICIT PROBLEM.

FURTHERMORE, WE ALL KNOW VERY WELL HOW MUCH DIFFICULTY WE ARE HAVING JUST IN MEETING CURRENT OBLIGATIONS UNDER THE MEDICARE PROGRAM. I REMIND YOU THAT WE STILL ANTICIPATE VERY SERIOUS DIFFICULTY IN KEEPING THE HOSPITAL INSURANCE TRUST FUND IN A SOLVENT STATE, ALTHOUGH WE HAVE MANAGED SO FAR TO KEEP PUSHING OFF THE DAY WHEN IT RUNS OUT OF MONEY.

WITH RESPECT TO LONG TERM CARE, ACCORDING TO A RECENT PAPER BY THE CONGRESSIONAL BUDGET OFFICE, FEDERAL EXPENDITURES ARE EXPECTED TO ALMOST TRIPLE BY THE YEAR 2000 ---- FROM 14 BILLION DOLLARS TO 45 BILLION DOLLARS IN CONSTANT 1985 DOLLARS. AND THE ASTONISHING THING ABOUT THAT ESTIMATE IS THAT IT IS BASED JUST ON CURRENT LAW. IT DOESN'T TAKE INTO CONSIDERATION THE ACUTE CARE CATASTROPHIC LEGISLATION PRESENTLY IN CONFERENCE OR ANY OTHER LONG TERM CARE PROPOSALS WHICH HAVE BEEN INTRODUCED IN THE CONGRESS. NOTE ALSO THAT THE ESTIMATE IS ONLY FOR THE PERIOD UP TO THE YEAR 2000. AND WE KNOW THAT THE BABY BOOM DOESN'T BEGIN TO RETIRE UNTIL THE YEAR 2009.

THIS WHOLE DEFICIT PROBLEM IS COMPOUNDED BY THE GREAT GROWTH WE ARE ANTICIPATING IN THE SOCIAL SECURITY TRUST FUNDS. ESSENTIALLY, THESE SURPLUSES MAKE THE CURRENT DEFICIT SEEM SMALLER THAN IT REALLY IS. IN 1993, THE SOCIAL SECURITY SURPLUS IS ANTICIPATED TO BE AROUND 100 BILLION DOLLARS. THIS IS THE YEAR, OF COURSE, WHEN BUDGET DEFICIT REDUCTIONS UNDER GRAMM-RUDMAN ARE SUPPOSED TO GET US TO A ZERO DEFICIT. UNFORTUNATELY, THE SOCIAL SECURITY TRUST FUNDS, AS REQUIRED ALSO UNDER GRAMM-RUDMAN, WILL NO LONGER BE COUNTED IN RECKONING THE DEFICIT AFTER THAT YEAR. HENCE, WHEN WE'RE DONE WITH GRAMM-RUDMAN, WE ARE GOING TO FIND OUTSELVES STILL FACING A DEFICIT WHICH IS ENORMOUS BY HISTORICAL STANDARDS.

THE WHOLE MATTER OF THE SOCIAL SECURITY TRUST FUNDS, OF COURSE, IS MORE COMPLICATED THAN SIMPLY COUNTING IT OR NOT COUNTING IT. BUT IT IS NOT MY PURPOSE TO GET INTO THAT HERE.

THE MAIN POINT I AM MAKING IS THAT WE NEED TO BE VERY CAREFUL BEFORE STARTING UP ANY NEW LONG TERM CARE PROGRAM, WHETHER IT BE THE CHAIRMAN'S ADULT DAY CARE PROGRAM, OR A MORE COMPREHENSIVE LONG TERM CARE PROGRAM AS WE ARE NOW BEING URGED TO DO BY MANY VOICES. THE REASON FOR THIS IS THAT ONE DAY THIS COUNTRY IS GOING TO HAVE TO DEAL WITH THE RETIREMENT OF THE BABY BOOM GENERATION, AND IT IS NOT CLEAR JUST HOW WE ARE GOING TO PROVIDE THEM WITH THE BENEFITS WE CURRENTLY PROMISE TO PROVIDE TO OLDER PEOPLE, TO SAY NOTHING OF PROVIDING THEM WITH YET NEW BENEFITS.

The CHAIRMAN. Thank you, Senator Grassley.

I think the point really is if the national average for adult day care centers is $31 in cost, how do we relate that obvious saving with somebody who is not in a nursing home or doesn't have to go to the hospital because they get the necessary health care and rehabilitation in an adult day care center? How do we relate that to savings and how do we project those savings?

I think we are having a difficult time really doing that at this point. I hope we can get some figures on that, because, obviously, the gross difference between $31 or an extra day or two or going back to a hospital just because that is the only place to go or into a nursing home—how do we project that if the adult day care centers become more widespread and are better used?

Obviously, it would be a saving. How much of a saving, we can't tell. I wish we could at this time, and I am hoping that we can begin to assemble some figures on that.

Senator CHAFEE. Well, Mr. Chairman, I am not sure it is obvious it will be a saving. As I understand the CBO figures, by 1992, it will cost an additional nearly $2 billion.

Am I correct in those statistics that I have? The ones I have on CBO, it costs $45 million in 1988, $130 million in 1989, $355 million in 1990, $800 million in 1991, and $1.8 billion in 1992.

I suppose the difference is that a lot of people who are currently being cared for now at home by families probably at considerable strain to the families and are not in nursing homes would be eligible under this program. I suppose that is where the difference comes in the spending.

Are you going to have any Administration witnesses?

The CHAIRMAN. Yes, we are going to have an Administration witness, and I think the point is we really haven't projected much in the way of savings on this, and I think there are obvious savings to offset some of the costs. So, I don't know that our CBO cost projections are accurate. That is my point.

Senator CHAFEE. Well, I think there is another virtue to it also, and that is I think that there is a humanitarian side to it as well. I think when an individual is able to be with their families and be part of the time in, say, a day care setting, with the companionship that comes there plus the warmth that is felt at home, these individuals will remain healthier in every aspect, physically and mentally.

Furthermore, in a day care setting, if there are problems, they can be spotted in advance. At least, that has been my experience in seeing them in action in my home State.

The CHAIRMAN. I think you are correct, Senator.

Before we go to our first witnesses this morning, I will ask unanimous consent that other members of the committee have permission to submit statements if they wish to do so, and those statements will appear in the record at this point.

[The prepared statements of Senators Heinz, Reid, and Pressler follow:]

OPENING STATEMENT OF

SENATOR JOHN HEINZ, RANKING MINORITY MEMBER

FOR THE SPECIAL COMMITTEE ON AGING HEARING ON ADULT DAY CARE

April 18, 1988

Mr. Chairman, I commend you for your timeliness and foresight in holding this hearing on Adult Day Care, and for your sponsorship of the Medicare Adult Day Health Care Amendments of 1987. I am pleased to be a cosponsor this legislation, which would establish Medicare coverage for up to 100 days each year of health and rehabilitative day care for Medicare eligible persons over the age of 18.

Throughout our recent consideration of legislation to protect older Americans from Catastrophic Health Costs, we heard repeatedly that the greatest financial risk borne by the elderly is long term care. We also know from many years of hearings and countless studies that the aged and disabled strongly prefer any form of long term care that will allow them to stay at home, rather than be institutionalized. Adult Day Care is one of several essential community based long term care services, such as home health and home supportive services, which are responsive to these needs and preferences of the elderly.

We have taken some significant steps toward improved coverage with the catastrophic care legislation approved by the Senate on October 27th. In that legislation, we improved the short term Home Health and Skilled Nursing Facility benefits provided by Medicare. Nonetheless, like Hercules in his struggle against Hydra, Congress faces a monster with more than one head. Providing for short-term acute care costs still leaves American families facing the greater financial catastrophe of a long-term, chronic illness.

Mr. Chairman, the typical recipient of Adult Day Care services is a woman over 73 years of age with an income of less than $500 each month, who relies upon her children to care for her around the clock. Adult Day Care centers offer critical daily services which help family caregivers to continue the very difficult task of supporting their disabled loved ones at home, by freeing them to work and attend to other business away from home during the daytime. Without this

assistance, thousands of families simply wear down and can no longer maintain their aged relatives at home. When family caregiving structures collapse, research shows, families must seek more expensive institutional care for their impaired loved ones.

Despite the vital role Adult Day Care is already playing in tens of thousands of lives across the country, most long term care legislation being offered in Congress omits coverage of Adult Day Care. I believe this is a mistake. Adult Day Care is an integral part of the long term care continuum of services, and should be recognized as such by any public chronic care program Congress may enact.

Adult Day Care can in fact meet the health and rehabilitative needs of many persons who would otherwise require care in a skilled nursing facility, including patients suffering from Alzheimers' disease. However, I think we should be careful in drawing any conclusions about cost savings from a Medicare Adult Day Care benefit. I say this because of the very high occupancy rates that characterize most States' nursing homes, and because of the long waiting lists of elderly and disabled beneficiaries awaiting entry to those nursing homes. The fact is, we have done such a poor job of financing long term care services that new benefits are needed simply to meet unmet needs -- and may not produce measureable financial savings.

Yet, for thousands of elderly and disabled persons and their families, Adult Day Care can make a tremendous difference in the quality of their lives. I believe it is wise public policy to target scarce Medicare resources to support and extend the service provided by the unpaid family caregivers who now assume the great bulk of long term care responsibilities in the United States. What's more, several polls of the American public suggest strongly that taxpayers are willing to pay higher taxes to ensure that resources for long term care are not as scarce in the future as they are today. Under these circumstances, Mr. Chairman, we would be remiss if we ignored Adult Day Care services as a key component of the array of long term care services that should be covered by Medicare.

Once again, Mr. Chairman, I thank you for convening this hearing, and join you in urging our colleagues in the House and Senate to join in a commitment to find a solution to the problem of long term care costs in the near future.

Opening Statement of Senator Harry Reid
Member
Senate Special Committee on Aging

April 18, 1988
"ADULT DAY HEALTH CARE: A VITAL COMPONENT OF LONG-TERM CARE"

Thank you, Mr. Chairman, for providing the members of this committee with an opportunity to explore the relatively new long-term health care service, adult day health care. I would also like to extend my sincere thanks to the distinguished panel of witnesses who are lending their valuable time to help us investigate this promising form of adult health care.

The video that opened today's proceedings is testimony to the positive ways in which adult day health care facilities can affect the medically needy and those who care for them. I firmly believe adult day care will prove to be an excellent form of long-term care. We will hear this morning how day health care for adults can significantly improve the quality of life for both the participants and their home caregivers, decrease medical costs by replacing or delaying nursing home stays, and decrease the number of costly visits to doctors and as well as the number of hospital stays.

My home state of Nevada has an ever increasing elderly, medically needy population. We have next to none of these adult day health care facilities, buy the few we have are very successful. In Reno, for example, the Washoe County Senior Center houses a very successful day health service called "Day Break." The facility serves its maximum capacity of 23, five days a week. There is consistently a waiting list. The director of the Center is hesitant to publicize the "Day Break" service because the Center simply cannot accommodate the numbers that would be sure to respond. Plans to expand the days of service and the size of the facility are being considered, but, as usual, funding is scarce.

It is obvious to me that the need for adult day health care is present, and that such facilities have the potential to decrease the health care bills of private citizens and of federal, state and local governments, while substantially increasing the quality of life for many.

SENATE SPECIAL COMMITTE ON AGING

HEARING ON ADULT DAY CARE

STATEMENT BY SENATOR PRESSLER

APRIL 18, 1988

Mr. Pressler. Mr. Chairman, I commend you and your staff for organizing this hearing on adult day care. Too often we have focused our attention and directed our resources to institutional care. With only five percent of the elderly population being in a nursing home at any given time, it becomes apparent that we must now direct our attention to community-based services. With an aging society, we can no longer allow a fragmented long-term care delivery system.

The population over age 75 is increasing. These individuals are more likely to be "at risk" from multiple chronic conditions. Adult day care can be an important program to keep frail older adults in the community.

Adult day care also can provide programs to the elderly with cognitive impairments, such as Alzheimer's disease. According to one survey by the National Council on Aging, it was estimated that 2,000 to 3,000 of the 10,000 to 15,000 adults currently in adult day care programs suffer from dementing diseases, such as Alzheimer's and related disorders. But many more of the estimated 1.5 to 2 million individuals who suffer from these diseases could be served by adult day care programs.

Adult day care can be a valuable support to family caregivers who provide 80 percent of all health care for the elderly. Elderly participants in adult day care who require continuous supervision are able to live with spouse or children in their own homes. Adult day care programs can reduce caregiver burnout. Some view this as the most significant factor in nursing home placement.

Advocates of adult day care state that this type of service is a cost effective way to deliver care to the elderly. In the state of South Carolina, an adult medical daycare package including physical therapy, meals, nursing care, personal care services, transportation and recreation costs $40 a day, as compared to a $60 charge for only the physical therapy at home.

Although reports from other states such as Hawaii, New Jersey and Massachusetts have been favorable to adult day care, some public policymakers still question the validity of the research data.

Extensive and comparable data often is lacking. Comparisons between the costs of day care and institutional and home care are difficult to make because the intensity of care provided at each level can vary greatly. Furthermore costs vary between day care centers which serve different kinds of individuals, provide different services or operate at different hours.

Lack of adequate transportation may create a barrier to those who are disabled and isolated in the communities. These individuals would benefit from adult day care. Buses may not be designed to carry wheelchairs and buildings may not be designed for the disabled. Policymakers have been questioning whether adult care will be cost effective in reducing admissions to more expensive nursing homes.

Although some may view adult day care solely as a respite or home health service, many view it as a separate service in the continuum of long-term care. Adult day care programs are multi-faceted, including medical services, counseling, rehabilitation, personal care services, meals, transportation, therapeutic and recreational services.

My visit to an adult day care center at the Huron Area Senior Center in Huron, South Dakota provided me with an example of an excellent program. By watching the activities at the Huron Centers, I know that adult day care can be of great assistance to both family caregivers and participants.

Adult day care can assist the elderly to maintain their independence, control, and quality of life. It can provide a way for the elderly to stay in their own homes in the community. Mr. Chairman, in a nutshell, independence, quality of life, and ties to the community sum up the advantages of adult day care. Thank you for holding this hearing to promote the dissemination of ideas on this very worthwhile and important program.

The CHAIRMAN. Our first witnesses this morning will be Jean and George Glaskas of Falls Church, Virginia.

Please proceed.

STATEMENTS OF JEAN AND GEORGE GLAKAS, FALLS CHURCH, VA

Mr. GLAKAS. Gentlemen, I am a little nervous, so you will have to bear along with me.

My name is George Glakas. I used to be a very active man with two jobs. When I was 63, I had a stroke that left me paralyzed on my left side.

I was in the hospital for three and a half months. From there, I went to the Woodrow Wilson Rehabilitation Center in Fisherville, Virginia for three months of therapy.

I got to the point where I could take a few steps, but I needed a lot of help and spent most of my time in a wheelchair. I was glad to go home, but my bed had to be in the kitchen, and there was no bathroom on that floor.

I was in bed most of the time, because I needed so much help to get up and out of bed. It was too much for my wife. I needed to have someone with me, dress me, feed me, do everything. I was a burden.

I was miserable and depressed. I couldn't go up and down the steps in the house, so we sold the house and bought a condo where everything is on one floor. We hired people to take care of me, but it was very hard to get somebody good, and it was expensive.

Money was really getting to be a problem with my wife and I. I still was in bed most of the time, feeling unhappy and guilty. I had to depend on my wife for so much.

Luckily, I had a young wife. [Laughter.]

That wasn't planned.

Senator CHAFEE. Young and attractive wife.

Mrs. GLAKAS. Thank you.

Mr. GLAKAS. I had a good family that helped me. My sister in Maryland located the day care center here in Virginia.

My first reaction was it is not my bag sitting around with old people, but when I went in 1985, I liked it and still do. I like the staff. They care about me and help keep my spirits up. I have made a lot of friends there. It has been really important to me to have friends to sit around with and talk to about current events and lie about our women. [More laughter.]

The center bus picks me up at my door and brings me home. At the center, we do many different things. We have competitive sports we can play like bowling, golf, volley ball, football, and baseball. That doesn't mean we go out on a football field and play. This is my football. We have box hockey. We even play against the other centers.

This year, we took first place in the volley ball tournament and second place in the box hockey.

We go to a movie occasionally and then out to lunch. We have trivia games to wrack what is left of our brains. We have singalongs and dances. Those dances are something; you should see

them. I do the wheelchair shuffle. When we have parties, I tell jokes.

We have lunch there, and I get only the foods on my special diet. There is a nurse to check my pressure and heart and to walk me, and there are other people to help me in whatever way I need.

Being at the center is much better than sitting at home. I can talk and enjoy myself. I can still lead a half-way decent life, a normal life.

I have one of two choices, the center or the nursing home, and I prefer the center 50 to 1. I only wish there were centers for people like myself in all 50 of the States.

Thank you, and please support us.

The CHAIRMAN. Thank you.

Mrs. Glakas.

Mrs. GLAKAS. I feel like most of my little speech has already been said. I have a lot of things that I have prepared here, but it is repeating, so bear with me.

I know you will be presented with numerous facts and figures today concerning Medicare and financing which we have already heard, but I would like to present the human or personal side of having these centers available from the care giver's point of view which is mine.

Some people might think of the center as a social club or a recreation club for the elderly. It is much more than that. It is exactly what the name implies, with the emphasis on care.

Before my husband started attending the day health care centers, we had tried all sorts of alternatives. Of course, we had family to help us, but since my husband needs assistance with all of his activities and his personal hygiene, any outside help that we had had to be considered "skilled."

Since he was declared totally disabled, it was necessary for me to work. Even then, we could not afford more than a few hours for someone to care for him and bathe him.

When I was at work, my husband spent most of his time in the bed. His condition deteriorated, and he was either watching TV or staring into space. He was hospitalized several times after falls and also for hip rotation from lack of exercise from staying in the bed too much.

He required much physical therapy. It became more difficult for me to assist him and transfer him from the wheelchair to his bed. He finally fell on me and crushed my hip.

At this point, our daughter came home from college to help us. During my recuperation, my sister-in-law was investigating possibilities for care of my husband. I would no longer be able to lower him down to a bathtub bench or to exercise him. She was referred to the Annandale Day Health Care Center.

He was accepted, and our routine changed drastically. My husband began to feel better and was much more alert. He looked forward to his days at the center which were filled with activities.

I was more relaxed about going back to work knowing that he was being well taken care of all day and that a nurse was on duty to check his health. A therapist was also made available through their efforts and also a podiatrist to cut his toenails which I couldn't do myself.

At first, I had to drop my husband off on my way to work, but, eventually, transportation was made available to us.

The financial burden was eased also, because the charge was based on a sliding scale.

The staff was also helpful to me in many other ways. When I developed carpal tunnel syndrome and was again faced with surgery and not being able to take care of my husband, they furnished me with a list of companions and other help which was available to me.

Middle income people of our generation have contributed to local, State, and Federal governments through our taxes all of our working lives. Saving for the future is almost impossible when you are trying to buy a car and a home and help children though college. All of a sudden, we are in our fifties, and we start to think of saving for 10 or 15 years for retirement.

Not many of us expect or plan for a major disabling illness when we are enjoying good health.

I realize it is a traumatic experience for my husband and for any person who has to spend the rest of his life in a wheelchair. But it is also a major upheaval in the life of the care giver.

The day health care center helps preserve the sanity of both parties. I think it has also prevented further hospitalization of my husband by keeping him active. It has also enabled me to continue working.

Even if we could afford a nursing home, neither of us would prefer that choice. The center is a much more agreeable arrangement for both of us. There is nothing else comparable or similar to a day health care center.

Had we not been able to avail ourselves of this opportunity, I don't know how we would have managed the past few years, financially or otherwise.

I am happy and honored to have met all of you today, and I hope you will consider making day health care centers available to anyone who is in need.

Thank you.

The CHAIRMAN. Thank you.

Mr. Glakas, you said at the outset that you were a little nervous, but that obviously hasn't taken away from your sense of humor. Do I detect that you spend just certain days in the day care center?

Mr. GLAKAS. Three days a week.

The CHAIRMAN. Like Mondays, Wednesdays, and Fridays?

Mr. GLAKAS. Monday, Tuesdays, and Fridays.

The CHAIRMAN. And then, on Wednesdays and Thursdays, what happens then?

Mr. GLAKAS. I mean Mondays and Thursdays.

Mrs. GLAKAS. Someone comes in.

Mr. GLAKAS. Someone comes in to take care of the house and she takes care of me. She bathes me and takes care of the house, does my wife's ironing. She has worked on occasion for us for 17 years, and she stays with me until my wife comes home.

The CHAIRMAN. On those two days a week?

Mr. GLAKAS. That is right, Mondays and Thursdays.

The CHAIRMAN. You said you pay for this on a sliding scale, Mrs. Glakas. How much is that?

Mrs. GLAKAS. The day care center?

The CHAIRMAN. Yes.

Mrs. GLAKAS. It is $8 a day for us. We were paying $9 an hour for help from other sources. When we had to get help from nurses aides who were considered skilled, we were paying $9 an hour for them to come in to take care of my husband.

The CHAIRMAN. Does the $8 include the meal?

Mrs. GLAKAS. At the day health care center, yes, it does include the meal. He has coffee in the morning, and he has lunch there.

Mr. GLAKAS. Yes, the Monocle caters the place. [Laughter.]

The CHAIRMAN. Thank you both very much.

Senator Shelby.

Senator SHELBY. Thank you, Mr. Chairman.

I just want to commend both of you for the courage to come here before this committee. I believe what you are doing is you are demonstrating here the need by testifying here for adult care centers, and you are showing as an example of what it can do for you.

Mr. GLAKAS. There is a need.

Senator SHELBY. I have long advocated that. I know myself of hundreds of people in my home State of Alabama that don't want to be in a nursing home, would like to stay at home as long as they could, but they have to have some type of support such as a day care center for adults and others.

I believe not only will it be cost effective—I mentioned this in my statement, because we have budgetary restraints—but it will be wholesome and be a lot better than warehousing people.

Mr. Chairman, I commend the people for coming here today.

Mrs. GLAKAS. Thank you.

The CHAIRMAN. Thank you, Senator.

Senator Chafee.

Senator CHAFEE. Thank you, Mr. Chairman.

We thank you for coming here today and giving us such a fine statement. It has helped us a great deal, and it gives us a perspective of how one family located a particular center.

Who operates this center? How does it finance itself?

Mrs. GLAKAS. The County of Fairfax, as far as I know.

Senator CHAFEE. It is a county operation?

Mrs. GLAKAS. I am sure that will be covered by testimony from other people. I don't know too much about the financial end of it, but we send our checks to the County of Fairfax.

Senator CHAFEE. Oh, I see. And how do they arrive at the sliding scale? They ask you what your income is and then determine——

Mrs. GLAKAS. Yes. When we first started, my husband wasn't working at all, and he wasn't declared disabled for six months. So, he actually had no income and was not on Medicare until he was 65. That was three years ago.

So, we had no Medicare. We had a minor hospitalization comprehensive plan, and I was not even working at the time except helping him with one of his jobs. He was working two jobs.

After he had his stroke, he was unable to work. So, I had to work.

Senator CHAFEE. So, what they do is they ask your income and then arrive at some kind of a figure.

Mrs. GLAKAS. Yes, that is right.

Senator CHAFEE. Well, that is good. I suspect that, judging from you and your husband said that, absent this day care center, it would be necessary probably for Mr. Glakas to be in some kind of a nursing home, wouldn't it?

Mrs. GLAKAS. We were faced with that possibility before the day health care center. After I broke my hip, I wasn't able to work.

We had spent a lot of money when he first had his stroke. We had a savings account, but that was wiped out because we didn't have full coverage for hospitalization. I didn't really know what I was going to do with him. As I said in my speech, we didn't have any other alternatives. I suppose we would have had to apply for some sort of State institutionalization.

Senator CHAFEE. So, this is a clear cut case where the presence of the day care center has made it possible for Mr. Glakas to remain at home.

Mrs. GLAKAS. Definitely.

Senator CHAFEE. Well, thank you both so much for coming.

The CHAIRMAN. Thank you, Senator.

Senator Grassley.

Senator GRASSLEY. Mr. Chairman, the questions I have I wouldn't expect the family here to be able to answer, but maybe for the benefit of the discussion that you and Mr. Chafee had previous to their testimony, it might be beneficial if we could maybe take four or five families from this day care center and, in relationship to their paying $8, find out how much comes from the family and how much comes from other sources and then compare that to what it would be if these people were in a nursing home.

Then we would have at least some real live examples of the savings that come from day care centers as opposed to being in a nursing home. Obviously, we all know that it is going to be cheaper, but I think that the $8 obviously doesn't reflect the real cost of what it would be for Mr. Glakas or anybody else to be there.

Would it be possible maybe to get some information like that?

Mrs. GLAKAS. Excuse me. How much would it cost for the government, if I had no income, to put my husband in a nursing home?

Senator GRASSLEY. Well, it is my understanding that that is about $20,000 a year, isn't it, Mr. Chairman?

The CHAIRMAN. That is correct.

Mrs. GLAKAS. As compared to $40 a day, five days a week for a year.

Senator GRASSLEY. Yes.

Mrs. GLAKAS. I don't know how to figure that out quickly, but it is still a lot less money.

Senator GRASSLEY. Yes, I think you are making my point for me. The only thing was if we could do something like that, Mr. Chairman, I would appreciate it very much.

The CHAIRMAN. Ms. Kay Larmer who is the director of this particular center will be a witness today, and she will be able to fill us in with those details.

Senator GRASSLEY. OK. I will read the record, Mr. Chairman.[1]

The CHAIRMAN. Senator Burdick.

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[1]See appendix, item 6, p. 117.

STATEMENT BY SENATOR QUENTIN BURDICK

Senator BURDICK. Mr. Chairman, I regret that I got to the committee late, but I ask that an opening statement of mine be made a part of the record.

The CHAIRMAN. Your statement will be part of the record, Senator.

Senator BURDICK. This is directed to either one of you. What kind of health professionals do you think need to be available to individuals in adult day care settings?

Mrs. GLAKAS. The people, I understand, that are at the day care center now are nurses. The director is a nurse, and I think there are several people who help her on the staff, and they also have volunteers.

Senator BURDICK. It is just nursing staff, then, at the present time?

Mrs. GLAKAS. I think there is only one. They probably need more than one, but at the present time, there is only one full-time nurse.

Senator BURDICK. In another area, how do you think the Federal Government can help address the need for adult care in rural areas?

Mrs. GLAKAS. I suppose a van could pick up people in rural areas the same as they do in urban areas.

Senator BURDICK. And take them to the professionals. Is that it?

Mrs. GLAKAS. I think so.

Senator BURDICK. Would you have any idea of how much this would cost to service?

Mrs. GLAKAS. I have no idea.

Senator BURDICK. That is all I have, Mr. Chairman.

[The prepared statement of Senator Burdick follows:]

Opening Statement from Senator Quentin Burdick on Adult Day Health Care

Thank you Mr. Chairman.

I commend you for your foresight in addressing the issue of Adult Day Care. Today, we have a rapidly increasing older population, especially in the age 85 and older category. Helping this population to manage with the chronic illnesses that often occur in the elderly remains a major challenge for the health care system in the next decade and beyond.

While the federal government will continue its support of research designed to eliminate or minimize the effects of debilitating diseases, the cure for many chronic illnesses remains to be found. In the meantime, support services for our aging population, and their caregivers are absolutely essential, and the demand for these services will steadily increase. I believe that S. 1819, Senator Melcher's bill and one which I am pleased to cosponsor, is an important step toward meeting these needs.

The need for day care services is especially great in rural areas of our country. As Co-Chairman of the Senate Rural Health Caucus, I am dismayed by the many letters I receive and conversations I have with elderly persons residing in rural North Dakota and other states across the country. These individuals have strong ties to their land and wish to stay in the small communities and farms where they have lived most or all of their lives. THeir children also have roots in these rural communities. Unfortunately, when an elderly spouse or parent requires support services because of physical or mental impairment, such structured programs in much or rural america cannot be found. With some assistance, many of the rural elderly could continue to live in their homes or with their children. Without day care and respite care services, the option simply does not exist. The toll on the caregiver becomes unmaneagable; it is too great. As a result, elderly in rural areas have no alternative except nursing home placement. I think that this should be the alternative of last resort, not the first choice, as it currently is in rural America.

Again, I thank you for providing the Committee with the opportunity to examine the tremendous potential that Adult Day Care may hold for our elderly and their families.

The CHAIRMAN. Senator Domenici.

STATEMENT BY SENATOR PETE DOMENICI

Senator DOMENICI. Mr. Chairman, could I just take two minutes with a couple of observations?

The CHAIRMAN. Certainly, Senator.

Senator DOMENICI. First, I want to thank you for convening this hearing to explore the role that adult day care can play in providing for long-term care for the American elderly. There can be no doubt that this is one of the most difficult issues facing our nation today and one that Congress is trying to examine thoroughly.

At a recent Senate Budget Committee hearing, we examined the long-term care problem and received some very useful comments, and I think today's testimony will add greatly to the discussion.

We spend over $50 billion each year on various services that are rendered to those who are disabled or chronically ill. With our population aging and long-term care costs rising faster than inflation, the Congressional Budget Office estimates that American long-term care costs could jump to over $150 billion by the year 2030 to 2050.

Given these prospects, obviously, we have to examine thoroughly the potential alternatives to institutionalization and their cost effectiveness and ability to help our senior citizens. So, we have to explore what should be a part of this whole continuum of long-term care.

Adult day care is one of the types of services that needs to be examined closely. I know how important it is to many of the elderly in my own State that have been able to remain at home and be part of their communities even though they may need some form of health care.

So, I personally look forward to these hearings. I am certain that they will be a part of our ultimate analysis and our final decisions as to how we can better serve our senior citizens with long-term health care.

I thank you for the hearing, and I am hopeful that this record will reflect some real options and alternatives that will be meaningful.

Thank you very much, Mr. Chairman.

The CHAIRMAN. Thank you, Senator.

And thank you, Josh and George Glukas, for your very insightful testimony.

Mr. GLUKAS. Thank you.

The CHAIRMAN. Our next witness is Ms. Lou Glasse, the President of the Older Women's League.

Ms. Glasse.

STATEMENT OF LOU GLASSE, PRESIDENT, OLDER WOMEN'S LEAGUE, ACCOMPANIED BY LAURIE SHIELDS, CO-FOUNDER, OLDER WOMEN'S LEAGUE

Ms. GLASSE. Chairman Melcher, thank you so much for including the Older Women's League in this opportunity to speak to you about the need for adult day care and for care givers.

I am Lou Glasse, President of the Older Women's League which is an organization that is devoted exclusively to the concerns of mid-life and older women.

You have received a copy of my testimony. I refer to a number of studies in it. I know because of the limitations of your time, however, that I need to limit my testimony. So, if you don't mind, Senator, I am going to give some highlights in our testimony and make a few comments about the hearing thus far.

I would like to begin by introducing to you Laurie Shields who is co-founder of the Older Women's League and co-author of our recently published book, "Women Take Care: The Consequences of Family Caregiving in Today's Society."

In researching the book, Laurie and her co-author, Tish Summers, who was also a co-founder of the Older Women's League and the OWL Task Force on Caregiving interviewed over 400 care givers.

One of the editors of that book and also on our task force is Linda Crossman, a day care director who is in your committee hearing this morning.

Let me say that our founding meeting in Iowa in 1980 the need for support for family care givers was paramount among the women who attended that first meeting. Daughters and wives were desperately trying to provide adequate care for their family members and at the same time, were often desperate for assistance in providing that care.

In the 8 years since the Older Women's League was organized, we are gratified with the increasing attention that has been given to the issue, and I am especially pleased that you have called this hearing today.

Services like adult day care, respite care, and in-home services are critical not only to the health of the cared-for but also to the health of the caregiver. Family caregivers are the unpaid workers in this nation's system of health care for the frail and dependent elderly.

As our nation has adopted cost containment measures to try to reduce Medicare costs, this has resulted in a greater shifting of responsibility to the families of our Nation requiring them to spend more and more of their time, energy, and money on the aged. This shift of greater responsibility for the family has occurred at a time when more and more women are entering the work force out of economic necessity.

So, the combination of the public policy of shifting discharged Medicare recipients into the home while, at the same time, more women are having to enter the work force is creating dilemmas for millions of women.

Women traditionally have been the care givers of both young and old. Almost three-quarters of the caregivers of the elderly are women, totalling over 1.6 million.

One thing, sir, that most people don't realize is that the average woman today can expect to spend as many years caring for a dependent parent or spouse as she did in caring for a dependent child. Laurie Shields recently told the Board of the Older Women's League about a woman who wrote that she was a 75-year-old woman caring for her 100-year-old mother and had been doing so

for 20 years. The women wrote that what she desperately needed and wanted most was one night's unbroken sleep.

Yet, women are expected to and do adjust their work schedules, their lives, to provide aid to their relatives. Most people are doing that, lovingly, willingly, regardless of the cost to themselves.

For many of them, this is indeed a treasured time which they wouldn't give up at all, as Mrs. Glakas so clearly illustrated. But also for many of them, it is a time of great pain and struggle and exhaustion not only physically but emotionally and financially which also Mrs. Glakas illustrated in her testimony.

Many caregivers are isolated, housebound, become depressed, and financially depleted. We know from studies that the health of many caregivers suffers as a result. All of us, I think, know of some caregivers who have risked their own health to care for their loved one.

However, the economic effects of caregiving can be equally devastating for women, and this has long-term implications that I hope your committee will consider, not only when they are thinking about the lesser cost of day care in contrast to skilled nursing home care, but also consider the long-term effect of the caregiver being out of the work force and what this means for her current income and future income.

We know from studies, that examined income of the aged over the next 30 years, that the poor old of tomorrow will be mostly women. Sir, this is largely due to women being in and out of the work force primarily because of family responsibilities. We know that, on average, women take 11 years out of the work force because of their family responsibilities whereas men have an average of only 1 year out of the work force.

This has a direct result upon their future income including vesting, pension policies, and their Social Security coverage.

We know that a large percentage of women who take time out to provide care are those who are working at minimal income. At the same time, there are some studies that indicate how much the income is that they give up annually in order to provide care to the aged.

Increasingly, some corporations are concerned about employees who are caregivers. Corporations that have looked at their work force, between 12 and 22 percent of their employees are providing care and this of course has a tremendous effect upon the individual productivity of the workers.

There are variations in these studies, but some companies are beginning to promote policies to sponsor adult day care, care giving fairs, provide flexible work hours, and take other approaches to make sure that they help their employee caregivers.

Most care givers like Mrs. Glakas are reluctant to seek services even when they are available or affordable. But, many times, services are not used because caregivers don't know about them.

However, often, these services are not available or not affordable. Also, we know that waiting until a crisis erupts before looking for services means that the choices will probably be more limited and the stress on both patient and caregiver will be greater.

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The incapacity of caregivers resulting from being over-burdened by caring for an aged person can truly deplete their physical resources.

Among the services noted in our book, Women Take Care, are adult day care, respite care, and home health care. As you have noted in your opening statement, Medicare does little to pay for those services now. It is focused exclusively on acute care.

At the same time, although Medicaid allocates 40 percent of its nationwide budget to nursing home care, a couple must impoverish themselves to qualify for Medicaid coverage.

Being considered, now, in conference is a critical bill that addresses spousal impoverishment. We hope that the conference will report out the most liberal support for the community spouse so that the community spouse is not impoverished for years as a result of needing to care for the aged one in need of skilled nursing care.

Private insurance offers virtually no assistance at this time to Americans requiring extended home care and skilled nursing home care.

In conclusion, we need national health policies that support families as they care for their incapacitated members. We need policies that are concerned for the well being of the caregiver as well as the person cared for. We need a Federal system of services for long-term care that will strengthen families who give care, not weaken them, that will nurture the caregiver, not exploit her.

Adult day care programs would be a major resource, a major assistance to those caregivers as well as to the cared for. Therefore, the Older Women's League urges the expansion of both Medicare and Medicaid to cover respite, adult day care, and home health care, and we applaud you, sir, for the promotion of S. 1839.

Thank you.

[The prepared statement of Ms. Glasse follows:]

OLDER WOMEN'S LEAGUE

NATIONAL OFFICE

STATEMENT OF THE OLDER WOMEN'S LEAGUE

for a hearing on

ADULT DAY CARE: A VITAL COMPONENT OF LONG TERM CARE

before the

U.S. SENATE SPECIAL COMMITTEE ON AGING

April 18, 1988

Chairman Melcher, members of the Committee. Good Morning. I am Lou Glasse, President of the Older Women's League, a national membership organization devoted exclusively to the concerns of midlife and older women. The Older Women's League was formed following the White House Mini-Conference on Older Women in 1980, and now has over 20,000 members and 100 chapters. Through education, research and advocacy we work for changes in public policy to eliminate the inequities older women face.

I would like to introduce to you Laurie Shields, co-founder of the Older Women's League and coauthor of our recently published book Women Take Care: The Consequences of Family Caregiving in Today's Society. In researching the book, Laurie, her co-author Tish Summers, and the OWL Task Force on Caregiving, interviewed over 400 caregivers.

National surveys have shown that caregivers are in desperate need of support services. Services like adult day care, respite care and in-home services are critical. Furthermore, our own research has shown that these services can substantially lift the emotional and economic burdens of caregiving.

Family caregivers are the unpaid workers in this nation's system of health care for frail, dependent persons. Without the attendance, assistance and nursing that caregivers devote to the elderly, our hospitals and skilled nursing facilities would be flooded.

As health care costs have risen over the last twenty years and as government has engaged in intensive cost containment policies, more and more responsibility for care of the sick and the aged has been shifted to families. Studies show that, for every person in a nursing home, there are four living in the community who receive unpaid care from families and friends. And because people are living longer, increasingly aging adults are caring for very aged parents.

This shift toward greater family responsibility has occured at a time when out of economic necessity more women are entering the paid labor force. These two events are causing personal and family disruption as well as economic hardship for millions of families and, particularly, millions of women.

Women traditionally have been the caregivers to both young and old. Roughly three out of four (72%) caregivers of the elderly are women, totaling 1.6 million. The most common relationship of caregiver to elderly care recipient is that of daughter or wife. Studies indicate that the average woman today can expect to spend as many years caring for a dependent parent or spouse as she does in caring for a dependent child.

We expect them to adjust their work schedules, their social and marital relationships their leisure time, indeed their lives, to provided succor to aged relatives. And more caregivers are doing just that--lovingly, willingly, regardless of the cost to themselves.

For many, this time of taking care of a loved one is a treasured time of sharing, a time to express love through tenderness, patience and understanding. But it can also be the backbreaking work of lifting, bending, turning, and of cleaning soiled bed linens. For many, this strenghtens and deepens the commitment of the caregiver and the cared for to each other, and it provides lasting memories. For some it is a time of pain, struggle and exhaustion that may stretch to a breaking point their capacity to care.

Sometimes too much is asked of caregivers. Frequently they carry the burden alone, housebound and isolated, often depressed and financially depleted, they may abuse the person dependent on them or may become ill themselves. A University of Bridgeport study found that 20% of caregivers it surveyed had been under a doctor's care and 22% of them suffered from frequent anxiety or depression. Most of us have known someone who has risked her own health in order to care for another. Among the 1.6 million women who are caregivers, almost half (44%) report they are in fair or poor condition.

The economic effects of caregiving can be devastating for women. Job interruptions for family responsibilities are a major factor in poverty among midlife and older women. Between the ages of 21 and 64, full-time women workers average 11.5 years out of the paid labor force, while men average 1.3 years. These differences are most extreme among midlife workers. For this group, full time women workers between the ages of 45 and 64 have spent almost two decades out of the paid labor force caring for family members, while men in this age category have spent less than one year away from work. This loss of job tenure has both a direct effect on present income, as well as on future retirement benefits. Job interruptions have also meant that vesting in a pension plan is often unlikely, even when retirement benefits are available.

The corporate community is increasingly turning its attention to the balancing act of working and caregiving. Employers have good reason to be concerned. A study conducted by the Family Survival Project looking at the joint demands of caregiving and employment found that 22% of those surveyed had quit their jobs because of a relative's caregiving needs. Of those who remained employed, 55% had to reduce the number of hours that they worked. More than half of those still employed reported decreased productivity. The study found that employed caregivers spent an average of 34 hours each week working and another 35 hours each week caring for their disabled relatives. These working caregivers spent as much time taking care of an ill or disabled adult as they spent at work. Those who left their work in order to care for a relative estimated lost income to be $20,400 a year. In addition, they spent an average of 18 hours a day giving care.

Other studies have confirmed these findings. Research by the Philadelphia Geriatric Center in 1987 and the National Center for Health Services Research and Health Care Technology in 1986 found that 12 percent of their samples of caregiving daughters had quit their jobs. A sampling of caregivers done by Elaine Brody in 1984 found that 40% of women who left their jobs for caregiving responsibilities had incomes under $15,000.

Many companies have begun to conduct their own studies. In December 1985 the Travelers Companies found that twenty percent of all its home office employees, aged 30 and older, provided some form of care for an older person. This survey found that these employees provided an average of 10.2 hours per week of care for an older person, with 8 percent of them spending 35 hours or more per week at the task. Forty percent managed the elderly person's finances, and 30 percent provided direct financial support. Other company surveys are finding the same results, creating concern about personal productivity. Many companies have instituted policies to help employed caregivers, such as corporate sponsored adult day care, caregiving fairs, flexible work hours and expanded leave policies.

Too often, caregivers are reluctant to seek services, even when they are available and affordable. A recent study found that three out of four of the disabled elderly, who reside at home, do not receive any formal service. Only 5% receive all their care from paid services. Many caregivers do not know that services exist. Some feel that they should be able to solve their problems on their own, without turning to outside help. Some feel guilty for wanting to get away from caregiving. Some are uncomfortable with a stranger coming into their home. Some feel that no one can care for their relatives as well as they can.

But waiting until a crisis erupts before looking for services means that the choices will probably be more limited and the stress on both patient and caregiver will be greater. Unfortunately, not all of the needed services are available. Though some are available, they are too costly.

Among the services noted in Women Take Care are adult day care, respite care and home health care. Paying for these services however, presents a serious problem for families. Medicare, the largest government payer of health care for older Americans is focused exclusively on "acute care", which in practice means hospital care.

Ironically, the health care containment policy adopted by the government with such fanfare occurred at the same time that the Administration's practice of Medicare reimbursement for home health aid service was quietly downgraded. The number of days covered was reduced and reimbursement became more restrictive. The patient is now required to be sick enough to be homebound and at the same time well enough to need only intermittent care. In other words, if the person is so sick that he/she requires skilled nursing services, services may be available in the home a few hours for a few weeks. Some health planners call this a NO-CARE ZONE.

Medicaid, on the other hand, allocates 40% of its nationwide budget to nursing home care, but a couple must impoverish themselves to qualify the disabled spouse for Medicaid coverage.

As you know, Medicaid may pay some home health care but eligibility criteria vary from state to state. In a few states Medicaid will pay for adult day care for a person is eligible.

Private insurance plans offer little assistance to the disabled spouse and caregiver once he leaves the hospital. There is a growing interest among some insurance carriers in offering long term care insurance but we have a long way to go before adult day care, respite care and adequate in-home services are available and affordable to families in need.

In conlusion, we need national health policies that support families as they care for their incapacitated members. We need policies that are concerned with the well-being of the caregiver as well as the person cared for. We need a federal system of services for long term care that will strengthen families who give care, not weaken them; that will nurture the caregiver, not exploit her.

More adult day care programs need to be established that will provide relief from constant caring and at the same time enable the caregiver to remain in the paid labor force. We need to encourage the development of more affordable respite care programs. The Older Women's League urges the expansion of Medicare and Medicaid to cover respite, adult day care and home health care.

The CHAIRMAN. Thank you, Ms. Glasse.

The Older Women's League is a fairly new organization, is it not?

Ms. GLASSE. We are 8 years old, sir. We have 20,000 members nationwide and we are growing very rapidly.

The CHAIRMAN. Then, you are in most States now?

Ms. GLASSE. We are in 37 States across the country. We have about 115 chapters. We are a grass roots organization of women who come together as a result of their concerns about the problems they are facing such as inadequate income and care giving.

The CHAIRMAN. Well, the book by Tish Summers and Laurie Shields, "Women Take Care," has provided us here on this committee with a beginning of understanding how much of a drag this is on women.

Laurie, in your documentation for this book—I think Ms. Glasse said that 75 percent of the care givers, that is, someone helping somebody at home, are women. Is that borne out by your——

Ms. SHIELDS. It certainly is, Senator, which does not say that we found men are not care givers. Men are caregivers, but they do it in a different way. They are able to pay for services that the dependent spouse cannot.

In addition, from a demographics point of view, women outlive men by 8 years now, and the gap is growing. As in the case of the Glakas', men are very often married to younger women who outlive them and will wind up becoming care givers.

I have been a care giver twice in my life, once for my husband—and I was younger than he was, and for Tish Sommers, my colleague and co-founder of the League.

However, the differences are more than just gender. What it is is an acceptance of a societal kind of dictum that says women are scheduled to do this because theirs is the nurturing role in the family.

As a wrinkled radical, let me be the first to tell you that I would like to have women have the same option men have, and that is to be able to say it is not my cup of tea; I can't do it—and not feel guilty about it.

In Senator Bradley's State of New Jersey, we have some wonderful programs going, and some of the most exciting ones coming out in other States—I just came from Georgia—are going for State respite care bills. Adult day care centers are another badly needed form of help.

Compassion is in very short supply in this country today, and we shouldn't load it all on the backs of unpaid women care givers. We need a new partnership. We need private sector, we need government, we need care givers, we need the whole works, even though we aren't going to get the whole enchilada.

However, with the help of people like yourself and the members of this committee who have long had a reputation that we are aware of of bringing to the fore problems of older people that nobody else wants to touch, believe me, this is a hot issue.

The CHAIRMAN. Thank you.

Senator Bradley.

STATEMENT BY SENATOR BILL BRADLEY

Senator BRADLEY. Mr. Chairman, I would only thank the witnesses for their testimony. I think they have been very helpful.

Ms. GLASSE. Thank you.

The CHAIRMAN. Thank you both very much.

Next, we are going to hear from Don Peterson who comes from my State. He is the Executive Vice President of St. John's Lutheran Home in Billings, Montana, a home that I have had the privilege of visiting several times.

Also, at the same time, we will call Ms. Kay Larmer, Chairperson of the National Institute on Adult Daycare, a membership unit of the National Council on Aging.

Please proceed, Don.

STATEMENT OF DON PETERSON, EXECUTIVE VICE PRESIDENT, ST. JOHN'S LUTHERAN HOME, BILLINGS, MT

Mr. PETERSON. Thank you, Senator.

I am Don Peterson, Executive Vice President of St. John's Lutheran Home in Billings, Montana.

You have copies of my written testimony, and I will only excerpt some of that to emphasize certain points.

St. John's is a multi-service provider which includes an adult day care center.

I want to emphasize I am here today representing the American Association of Homes for the Aging, a national non-profit association which represents more than 3,200 non-profit providers of long-term care, health services, housing, and community services for the elderly.

On behalf of AAHA, I would like to thank the committee for providing this opportunity to testify about this country's need for adult day care. I would also like to thank you, Senator, for the support you have given to the adult day care issue in the United States Senate.

The introduction of S. 1839 is an important step in making this health care option available to additional numbers of older Americans.

The National Institute on Adult Daycare has noted that adult day care programs have risen from 12 in the early 1970's to nearly 1,400 today. This is certainly progress, but you and I know that we have barely scratched the surface. There is such a great need for this kind of program.

I think our program at Billings is an example of the kinds of individuals who need this service. We have a total of 16 participants who spend from 1 to 5 days per week at our center. They range in age from 65 to 92.

Some are there because of dementia. Some have chronic health problems. Some are lonely and just come for the company and socialization.

Adult day care programs are designed to provide socialization for the participants and, at the same time, address their health needs. In addition to medical monitoring and medication assistance, we provide psychosocial, recreational, and other programs for participants who have degenerative or chronic conditions. We also ad-

dress their nutritional needs with a daily lunch and an optional breakfast service.

In addition to meeting the specific needs of participants delineated above, I believe our program has made valuable contributions to three other social concerns which confront this country. The first is the need to maintain and enhance the ability of family care givers to continue their roles. Second, is the desire by all of us to promote the elderly person's independent living as long as possible. Third, is the ability to use limited fiscal resources to reach as many individuals as possible.

Let me expand on these three just a bit.

First is maintaining and expanding the role of the family care giver.

Family members provide 80 to 85 percent of the care given to our elderly. These care givers, many times, are retired spouses of the individuals who need assistance.

More and more frequently, however, care givers are middle-aged wage earners who struggle to balance the demands of their jobs with the responsibility of caring for aging persons.

All these care givers need the kind of support which adult day care can provide. For those retired spouses, adult day care can relieve the isolation and other stresses that may eventually impair the ability of that care giver to live independently.

For employed care givers, the respite provided by adult day care can help them to continue their own growth and establish a financial base for their own retirement years. It also permits many of these individuals to contribute economically to the welfare of their parents.

My second point is promoting independent living.

Behind the phrase "promoting independent living" is the implicit intention of avoiding nursing home placement. Although I feel very strongly that there is a place for the nursing home in the overall continuity of care, I do share the value that there is no substitute for independent living if that individual can remain healthy and safe.

I believe adult day care centers can provide this environment for many, many individuals. Day care can also help some elderly persons over the rough spots which might otherwise result in nursing home placement.

We had an example of that in our own center not long ago. An 86-year-old woman who lost her husband, became depressed, confused, over-medicated, and eventually ended up in the hospital.

She entered our day care program after six months of treatment and therapy, both in the hospital and in the community. Within six weeks, she was able to move into our retirement home, where she continues to function well.

This was a case in which the nursing home staff worked with the day care staff to successfully avoid nursing home placement. We believe that this teamwork has helped most of our participants avoid or at least delay placement in nursing homes.

My third issue is the efficient use of limited resources.

We are all concerned about health care costs, and nursing home costs have especially captured public attention. The program at St. John's not only reduces the State and national burden of nursing

home costs, because nursing home placement is avoided, but it also uses nursing home resources to reduce the cost of adult day care.

At St. John's, our arrangement permits us to offer a broad range of health and social services, utilizing the expertise of specialists in nursing, dietetics, social work, and activities for $16 a day, including lunch. A participant who comes to our center five days a week for a full day pays $80 a week for these services. That totals a little more than $4,000 per year compared to $18,000 to $22,000 for nursing home care.

In conclusion, allowing the elderly to maintain their independent life styles, reducing stress on the family members who care for them, and doing so in an economic manner is a challenge we hope many others will accept.

Again, we appreciate this opportunity to share these ideas with you and thank you again for the support you have provided for this very important issue.

Thank you.

[The prepared statement of Mr. Peterson follows:]

Statement of

DONALD A. PETERSON

Executive Vice President
St. John's Lutheran Home
Billings, Montana

On behalf of

The American Association of Homes for the Aging

Chairman Melcher, members of the Special Committee on Aging, I am Donald A. Peterson, Executive Vice President of St. John's Lutheran Home in Billings, Montana. St. John's is a multi-service provider of independent retirement living, intermediate and skilled nursing care, respite care, Alzheimer's programs, information and referral services, and adult day care. I am here today representing the American Association of Homes for the Aging (AAHA), a national nonprofit association which represents more than 3,200 nonprofit providers of long term care, housing and community services for the elderly.

On behalf of AAHA, I would like to thank the Committee for providing this opportunity to testify about this country's need for adult day care services. I would also like to thank you, Mr. Chairman, for the support you have given to the adult day care issue in the U.S. Senate. The introduction of S. 1839 is an important step in making this health care option available to additional numbers of Americans. As the National Institute for Adult Daycare (NIAD) has noted, the number of programs has risen from fewer than 12 in the early 1970's to nearly 1,400 today. That is certainly progress. I can tell you from my experience, and that of my AAHA colleagues, however, that the number of centers at the present time does not scratch the surface of day care needs presented by our elderly citizens and their adult children.

I think my own program in Billings presents a good cross-section of the kinds of individuals who need this service. We have a total of 16 participants, who spend from one to five days per week at our center. Our current participants range in age from 65 to 92 years. Seven of these participants have some degree of dementia, sometimes combined with a medical condition. Eight of the participants have some kind of chronic health problem without dementia (i.e., heart or post-stroke problem). And our oldest resident, a 92-year old woman, comes just for the company—she has outlived her oldest friends. A lot of our participants come for the socialization value, in fact. After all, your children, even when they are grown, are still your children, not your peers. Adult day care programs are designed to provide socialization for the participants at the same time

they address their health needs. In addition to medical monitoring and medication assistance, we provide psychosocial, recreational and other programs for our participants who have degenerative or chronic conditions. We also address their nutritional needs, with daily lunch and an optional breakfast service.

In addition to meeting the specific needs of participants, I believe our program has made valuable contributions on three major societal issues: (1) the need to maintain and enhance the ability of family caregivers to continue their roles; (2) the desire of all of us to promote the elderly person's independent living as long as possible, and indefinitely if we can; and (3) the need to use limited fiscal resources to reach as many individuals as possible.

Maintaining and Expanding the Role of Family Caregiver.

Family members provide 80-85 percent of the care given to our elderly. These caregivers many times are retired spouses of the individuals who need assistance. More and more frequently, however, caregivers are middle-aged wage-earners who struggle to balance the demands of their jobs with the responsibility of caring for aging parents.

All these caregivers need the kind of support which adult day care can provide. For those retired spouses, adult day care can relieve the isolation and other stresses that may eventually impair the ability of even the caregiver to live independently. For employed caregivers, the respite provided by adult day care can help these wage-earners continue their own growth and establish a financial base for their own retirement years. It also permits many of these individuals to contribute economically to the welfare of their parents. For all caregivers, adult day care cent[illegible] can serve a teaching as well as a caring role. Both participants and caregivers can be instructed in new or alternative ways of meeting the elderly individual's needs. This educational effort can enhance the quality of the at-home care.

Promoting Independent Living.

Behind the phrase "promoting independent living" is the implicit purpose of "avoiding nursing home placement." As the director of an organization which contains what I believe is a very fine nursing home, I don't share the view of some that every nursing home is a dungeon to be avoided at all costs. But I do share the value that there is no substitute for independent living, if the individual can remain both healthy and safe. I believe adult day care centers can provide this environment for individuals who have help during the evening hours but who would be alone, and vulnerable, during the day.

Day care can also help some elderly persons over the "rough spots" which might otherwise result in nursing home placement. We had an example of that in our own center not long ago. An 86-year old woman from another area of the state was widowed in early 1987. Shortly after that, she was admitted to the hospital—depressed, confused, and over-medicated. She was in psychotherapy for four months, during which time her family sold her home and moved her to Billings where the family lived.

She entered our day care program shortly after the move. We had a special arrangement to offer her because our day care program is physically located in our nursing home. During her time in day care she received the support services of both the day care and nursing home staff on her health and social needs. Within six weeks she was able to move into a retirement home, where she continues to function well.

This was a case in which a nursing home staff worked with a day care staff to successfully avoid nursing home placement. We believe that this teamwork has helped most of our participants avoid, or at least delay, institutionalization. Of course, if the widow I mentioned had not been able to recover as she did, and had been admitted to the facility, she would have had an opportunity to work with the staff before admission. We believe that would have eased her transition somewhat.

Efficient Use of Limited Resources.

We are all concerned about health care costs, and nursing home costs have especially captured public attention. The program at St. John's not only reduces the state and national burden of nursing home costs, because nursing home placement is avoided, but it additionally uses nursing home resources to reduce the costs of adult day care! The frequently-quoted average cost of adult day care is $30-$35 per day. At St. John's our arrangement with the nursing home permits us to offer a broad range of health and social services, utilizing the expertise of specialists in nursing, dietetics, social work, and activities for $16 per day, including lunch. A participant who comes to our center five days a week for a full day, pays $80 a week for those services. That totals a little more than $4,000 per year, compared to $18,000-22,000 for nursing home care.

Conclusion

Allowing the elderly to maintain their independent life styles, reducing stress on the family members who care for them, and doing so in an economic manner is a challenge we hope others will accept. We appreciate this opportunity to share these ideas with you Mr. Chairman, and thank you again for the support you have provided on this very important issue.

The CHAIRMAN. Thank you, Don.
Ms. Larmer.

STATEMENT OF KAY LARMER, CHAIRPERSON, NATIONAL INSTITUTE ON ADULT DAYCARE, NATIONAL COUNCIL ON THE AGING

Ms. LARMER. Senator Melcher and committee members, I am Kay Larmer, coordinator of Adult Day Health Care Programs for Fairfax County and also Chairperson of the National Institute on Adult Daycare, a membership unit of the National Council on Aging.

The National Council on Aging, founded in 1950, is a national, non-profit organization. Its membership includes individuals, voluntary agencies, and associations, business organizations, and labor unions united by commitment to the principle that the nation's older people are entitled to lives of dignity, security, physical, mental, and social well being, and to full participation in society.

The National Institute on Adult Day Care is the only organization composed of professionals in the field working to develop and expand the adult day care field, to advocate for those who rely on adult day care services for daily and continuing support, and for those working to ensure that adult day care is of the highest quality, based on solid standards of excellence and available throughout the nation.

I am very pleased to be here today and have the opportunity to testify on behalf of this service and its benefits to older people and their families.

You have all received copies of my testimony. In fact, most of what I have said in my testimony has been eloquently said by the Senators and people that came before me.

During the past 10 years, adult day health care has developed to meet the needs of the ever-increasing frail and impaired population in our country. It provides a variety of services and activities that enable impaired adults to remain in their homes and communities.

As the term implies, adult day health care is a program of care during the day in a protective group setting. It is an innovative and effective way to organize and blend traditional health and social services for impaired adults.

Although adult day care is not a new concept, it is still not an integral part of the long-term care system in many areas. It was first introduced in the 1960's, but it has been very slow to develop, largely due to the lack of stable funding sources.

In 1973, there were only 15 programs. Today, however, there are 1,400 serving approximately 66,234 persons daily. This growth has been largely a grass roots effort, developing without any national initiative or coordinated funding source. In fact, it has occurred in spite of a public policy that long has favored institutional care.

Programs have sprung up throughout the country under the auspices of a variety of sponsoring organizations, both public and private. The majority are non-profit. They are located in churches, hospitals, multi-purpose senior centers, elderly housing projects, nursing homes, and homes for the aged.

The average per diem cost for adult day care is $27. Earlier, it was mentioned that it is $31, and that is if you include the in-kind

services that most programs have. Still, it is much less than the cost of other forms of long-term care.

At present, most programs rely on multiple funding sources which include Title XIX, Medicaid, and Title XX of the Social Security Act of the Older Americans Act, Title III, client fees, foundations, and philanthropic support. A few receive reimbursement through private insurance carriers, and, in some instances, the Veterans' Administration is reimbursing veterans for this service.

At present, there is little local funding from counties for adult day health care, and what funding exists is mostly in kind.

Most adult day care programs are staffed by a multi-disciplinary team, as you have heard from testimony before mine.

Though adult day health care programs are group programs, they are also tailored to meet each participant's need and preference. Adult day care offers an individual plan of care, based on a person's functional assessment. Each participant is provided the opportunity to socialize and participate in health, social, recreational, and therapeutic activities that maximize his abilities and independence.

A diagnosis is not looked at with a participant when they come into the center, but we look at how they function and what we can do with what functioning level they have.

Probably the most important aspect for helping the individual is the atmosphere of expectation and hope. It consists of respect for the individual's latent strengths and the belief that some improvement is possible and the provision of the opportunity to try.

Those most likely to benefit from participation in adult day care programs are persons who would otherwise be substantially homebound or institutionalized. Recent State evaluation reports document these benefits. Adult day care assists the participant, his family care giver, and is a cost effective and efficient method of health care delivery, as you talked about earlier.

Adult day care restores and rehabilitates someone to their highest level of functioning. Every center can testify to the small miracles that occur such as the former stroke patient who learns to walk again through regular health monitoring, through nursing care, personal care, and enjoyment found with just being with friends.

Others are maintained at their highest level of functioning, thus preventing further decline and debilitation. In California, recent studies documented this and found that 87 to 96 percent maintained or improved in functioning.

This is saying something when you consider the average age of adult day center participants ranges from 72 to 76.

For the care giver, as Lou Glasse talked so eloquently about, the benefits of adult day care have become increasingly recognized. Families provide 80 percent of all health care for the elderly, and I don't think this is stressed enough. It really is families that are providing the health care in our country today.

Business surveys are identifying that up to 35 percent of employees are providing some form of care giving to their older family members. It is not surprising in this country which has a majority of two career families that research is showing that care giver

burnout is the most significant factor in nursing home placements, not the physical and health status of the older person.

At our centers, we find that we can continue to provide for very impaired people. It is generally when the family burnout is to the point where they can no longer continue to care for someone at home that the decision to place them in a nursing home occurs.

Family resources are not unending. Fatigue, lack of personal time, mobility of family members, financial costs, and the need or desire of family care givers to seek employment lead to stress and eventual breakdown in the family's efforts.

Adult day care is a valuable service as it provides respite to the care givers and relieves stress, enables them to continue to work, and helps employee productivity.

For the government it helps. By utilizing the benefits of a group setting, adult day health care costs less than the one to one provision of home health care and other institutional care services.

For example, under the Medicaid waiver program administered by the State of South Carolina, an adult day care medical package including a physical therapy service costs $40 a day as compared to a $60 charge for only the physical therapy services in the home. The center package also includes a full day of programs, meals, nursing care as needed, personal care services including bathing, recreation, and transportation.

Evaluation reports from other States such as Hawaii, New Jersey, and Massachusetts also indicate State satisfaction with adult day care's costs and their effectiveness.

At On Lok Senior Health Services in California, it was found that the use of adult day care was a vital component in the reduction of hospitalization. The monitoring and supervision of health status at the adult day health care center enables On Lok to prevent small health problems from becoming major problems needing hospitalization.

The hospitalization rate for On Lok's elderly persons certified for nursing home care is .7 percent of enrollment days, less than one-third that expected for this population and even lower than that for the general 65 and over population which is 1.1 percent.

Remember, these people were certified for nursing home care.

Senators, NIAD and NCOA need your help. If we are to continue to grow and expand to meet the changing health needs of this ever growing elderly population, we need Federal legislation. NIAD believes Medicare funding as proposed in S. 1839 is required for the following reasons:

Medicare coverage for adult day health care will make it accessible to those low and middle income persons who do not meet the income eligibility requirements for Medicaid or social services block grants but cannot afford to pay for these services. It also will help prevent the older person from becoming impoverished before he or she becomes eligible for care, as you mentioned earlier, Senator.

Medicare is a trend setter for private health insurance coverage. Medicare coverage will point the way toward inclusion of adult day health care in long-term care policies.

Currently, we do have three insurance companies who do include us in their package.

Medicare funding will result in the development of national certification standards and a method of quality assurance. Although NIAD and NCOA have developed national standards, they are generic and voluntary. It would be helpful to the field to ensure that centers provide quality programs through a national certification process.

NIAD and NCOA would be happy to work with HCFA not only in developing standards for certification but also for procedures and training for State employees.

Medicare reimbursement would also increase center resources, thus enabling those centers who wish to qualify for certification to add additional services if needed.

In my opinion, we have about 50 to 65 percent of the persons currently enrolled in adult day care who would be eligible under the intermediate care or skilled care criteria for nursing home care.

Senators, adult day health care has had over 10 years of experience. It exists in every State. The fact that four bills in Congress include adult day care means there is growing interest and recognition of the value of this service.

NCOA/NIAD believes the time for Federal legislation is now. We do not need further research, studies, or demonstrations. Financially, we cannot wait. Clearly, the present system is insufficient, inequitable, and bankrupts our Nation's frail and impaired population.

Thank you.

[The prepared statement of Ms. Larmer follows:]

Testimony

of

The National Council on the Aging, Inc.

and

The National Institute on Adult Daycare

Before The

Special Committee on Aging

United States Senate

April 18, 1988

Presentation to

Senate Special Committee on Aging

Monday, April 18, 1988

Senator Melcher, Honorable Committee Members, I am Kay Larmer, Coordinator for Fairfax County's Adult Day Health Care Centers and past Chairperson of the National Institute on Adult Daycare (NIAD), a membership unit of the National Council on the Aging, Inc. (NCOA), the National Council on the Aging, Inc., founded in 1950, is a national nonprofit organization. Its membership includes individuals, voluntary agencies and associations, business organizations and labor unions united by a commitment to the principle that the nation's older people are entitled to lives of dignity, security, physical, mental and social well-being, and to full participation in society.

The National Institute on Adult Day care is the only organization composed of professionals in the field working to develop and expand the adult daycare field, to advocate for those who rely on adult daycare for daily and continuing support and care, and for those working to ensure that adult daycare is of the highest quality, based on solid standards of excellence and available throughout the nation.

I am very pleased to be here today and have the opportunity to testify on behalf of Adult Day Health Care and its benefits to older people and their families/caregivers.

Though the majority of older persons can be expected to live out their lives with minimal difficulty, there is an alarming increase of older people who have major disabilities and chronic diseases. There are well documented statistics, which I am sure this Committee has on record, about the increasing number of people over age 75, persons most likely to be "at risk" and more susceptible to impairments. These statistics coupled with the high cost of institutional care, the long waiting lists for nursing homes, and the large numbers of inappropriate and premature institutional placements, have mandated the development of cost effective, yet quality community-based care for the nation's frail and impaired adults.

During the past ten years, Adult Day Health Care has developed to meet the needs of this population. It provides a variety of services and activities that enable impaired adults to remain in their homes and communities. As the term implies, adult day health care is a program of care during the day in a protective group setting. It is an innovative and effective way to organize and blend traditional health and social services for impaired adults. Although day health care is not a new concept, it is still not an integral part of long term care in many areas. It was first introduced in the early 1960s, but it has been very slow to develop largely due to the lack of stable funding sources. In 1973 there were only 15 programs nationwide; today however, there are over 1400 serving approximately 66,234 persons daily. This growth has been largely a grassroots movement.

developing without any national initiative or coordinated funding source. In fact, it has occurred in spite of a public policy that has long favored institutional care.

Programs have sprung up throughout the country, under the auspices of a variety of sponsoring organizations, both private and public. The majority are nonprofit. They are located in churches, hospitals, multipurpose senior centers, elderly housing projects, nursing homes, and homes for the aged. The average per diem cost for adult day health care is $27. Much less than the cost of other forms of long term care. At present, most programs rely on multiple funding sources which include Title XIX (Medicaid), Title XX (Social Services), Title III (Older American Act), client fees, foundations and philanthropic support. A few receive reimbursement through private insurance carriers and in some instances, the Veterans Administration is reimbursing veterans for the service. At present there is little local funding from counties for adult day health care and what exists, is mostly inkind support.

Most adult day health care programs are staffed by a multi-disciplinary team. Though programs vary enormously in focus and resources, it is generally agreed that staff should include or have available as consultants the following: nurses, social workers, occupational therapists, speech therapists, physical therapists, and recreation therapists. Physicians also play an important role in working with center staff to develop an appropriate individual plan of care.

Though adult day health care programs are group programs, they are also tailored to meet each participant's need and preference. Adult day health

care offers an individual plan of care, based on a person's functional assessment. Each participant is provided the opportunity to socialize and participate in health, social, recreational and therapeutic activities that maximize his/her abilities and independence. Probably the most important aspect for helping the individual is the atmosphere of expectation. It consists of respect for the individual's latent strengths, the belief that some improvement is possible and the provision of an opportunity to try.

Those most likely to benefit from participation in adult day care programs are persons who would otherwise be substantially homebound or institutionalized. Recent state evaluation reports document these benefits. Adult day health care assists the participant, his/her family caregiver, and is a cost effective and efficient method of health care delivery.

FOR THE PARTICIPANT

Adult day health care restores and rehabilitates someone to their highest level of functioning. Every center can testify to the small miracles that occur such as the former stroke victim who learns to walk again with the proper therapies, nursing management, personal care attention and enjoyment found with just being with friends. Others are maintained at their highest level of functioning, thus preventing further decline and debilitation. In California this was documented in their evaluation study in 1982 which found that 87 to 96 percent maintained or improved in functioning.

FOR THE CAREGIVER

The benefits of adult day health care to family/caregivers have become increasingly recognized. Families provide 80 percent of all health care for the elderly and recent business surveys are identifying that up to 35 percent of employees are providing some form of caregiving to their older family member. It is not surprising in this country, which has a majority of two-career families, that research is showing that caregiver burnout is the most significant factor in nursing home placement, not the physical and health status of the older person. Family resources are not unending. Fatigue, lack of personal time, mobility of family members, financial costs and the need or desire of caregivers to seek paid employment often lead to stress and eventual breakdown in the family's efforts. Adult day health care is a valuable service, as it provides respite to the caregiver and relieves stress, enabling the caregiver to continue providing care, and helps employee productivity.

FOR THE GOVERNMENT

By utilizing the benefits of a group setting, adult day health care costs less than the one-to one provision of home health care. For example, under the Medicaid Waiver Program, administered by the State of South Carolina, an adult medical daycare package, including a physical therapy service, costs $40 a day as compared to a $60 charge for only the physical therapy session in the home. The center package at $40 also includes a full day of meals, nursing care as needed, personal care services, including bathing, recreation and transportation, in addition to the therapy. Evaluation reports from other states such as Hawaii, New Jersey, and Massachusetts also indicate

state satisfaction with adult day health care's costs and effectiveness.

At On Lok Senior Health Services in California, it was found that the use of adult day health care was a vital component in the reduction of hospitalization. The monitoring and supervision of health status at the adult day health care center, enables On Lok to prevent small health problems from becoming major problems needing hospitalization. The hospitalization rate for On Lok's elderly persons certified for nursing home care is .7 percent of enrollment days, less than one third than expected for this population, and even lower than that for a general 65+ population (1.1 percent).

Senators, NIAD/NCOA needs your help. If we are to continue to grow and expand to meet the changing health needs of the ever growing elderly population, we need federal legislation. NIAD believes Medicare funding (as proposed in S1839) is required for the following reasons:

1. Medicare coverage for adult day health care will make it accessible to those low and middle income persons who do not meet the income eligibility requirements for Medicaid or Social Services Block grant but cannot afford to pay for these services. It also will help prevent the older person from becoming impoverished before he/she becomes eligible for care.

2. Medicare is a trend-setter for private health insurance coverage. Medicare coverage will point the way towards inclusion of adult day health care in long term care policies.

3. Medicare funding will result in the development of national certification standards and a method of

quality assurance. Although NIAD and NCOA have developed national standards, they are generic and voluntary. It would be helpful to the field to ensure that centers provide quality programs through a national certification process. NIAD/NCOA would be happy to work with HCFA not only in developing standards for certification but also procedures and training for state employees.

4. Medicare reimbursement would increase center resources, thus enabling those centers who wish to qualify for certification to add additional services, if needed.

Senators, adult day health care has had over ten years of experience. It exists in every state. The fact that four bills in Congress include adult day care means there is a growing recognition of the value of this service. Insurance companies, such as Aetna, Travelers, and Prudential, are beginning to recognize the importance of this service and include it in their benefits. A few states have funded this program. NIAD/NCOA believes the time for Federal Legislation is now! We do not need further research, studies or demonstrations. Financially we cannot wait. Clearly the present system is insufficient, inequitable and bankrupts our nation's frail and impaired population.

The CHAIRMAN. Thank you.

Don, the non-profit American Association of Homes for the Aging—and I stress every word of that, non-profit homes for the aging—is it true that there are over 3,200 homes for the aging in that association?

Mr. PETERSON. That is right. They represent nursing homes, housing programs, continuing care retirement communities, and some community service providers.

The CHAIRMAN. And you are a director of that association?

Mr. PETERSON. I am a former board member. I am presently on the House of Delegates for that organization.

The CHAIRMAN. How much experience have you had personally at St. John's?

Mr. PETERSON. I have been there over 15 years, Senator.

The CHAIRMAN. Over 15 years.

Mr. PETERSON. That is right.

The CHAIRMAN. And was adult day care a part of St. John's when you started 15 years ago?

Mr. PETERSON. No, it was not. We have had our adult day care program for about four years.

The CHAIRMAN. How many of the membership—or do you know—of the American Association of Homes for the Aging, the non-profits, how many of those 3,200 have adult day care centers?

Mr. PETERSON. There are over 300 of them that now have adult day care programs, and that has roughly doubled in the last four years.

The CHAIRMAN. Then, I conclude it is your experience that in nursing homes, this is a part of most of them or should be a part of most of them or all of them?

Mr. PETERSON. Well, it is roughly 10 percent right now.

The CHAIRMAN. Yes, I understand that, but the trend seems to be upward. Should it be part of most or all?

Mr. PETERSON. It certainly is a trend. I think that is an individual decision that will be made by each of these facilities depending on a number of factors.

We happened to have some space in our facility and a demand in our community that makes a program possible. There were no other adult day care programs, and we felt that there was a need. By expanding our program, that is adding an adult day care program to our comprehensive service package at St. John's, we are able to meet this need.

Obviously, that is not going to work at every facility, because they won't have the space or programs that they can expand.

The CHAIRMAN. Ms. Larmer, you said this is grassroots and that the cost of providing it is sort of scattered between local and donations and States—do any of the States provide any help?

Ms. LARMER. Some States do. Some States provide start-up money for programs. Some States provide funding through Title XX, the matched grant moneys. Some States provide separate special allocations every year for scholarships for certain programs, but not the majority of States, no.

The CHAIRMAN. Last year when we were considering what could become a help in catastrophic coverage, in visiting with HHS, I found that a number of people in nursing homes throughout the

country, 1.5 or 1.3 million or whatever figure one chooses to take, was about tripled or more by the number of people who were identified as older Americans who had to have home health care.

I am beginning to believe that perhaps adult day care centers are the place to start on home health care. Am I beginning to look at this in the right perspective? What is your judgment on this?

I notice you have not only a degree in nursing but also a master's in family and community development.

Is it your opinion that this is the place to start with adult day care centers for helping older Americans who need health care at home?

Ms. LARMER. I believe that we need to look at the whole long-term care system. It is almost a package, and we need to identify what services someone needs to be as independent as possible.

As Mr. Glakas referred to, he comes to the day care center three times a week, he utilizes home care several other times a week, and I feel that it can be a combination of services that someone needs. Some people will need to come to adult day care five days a week and require additional services on the weekends.

Some people, really, if it is just for respite care for the care giver, may require just two days a week at the day care center and require no home care.

What is happening at our day care centers in Fairfax County is we are designing our centers to include a functioning clinic with bathing facilities for handicapped people. So, we are providing a lot of the personal care that used to be provided in home care.

However, what we found was that when someone had to stay home just for that bath and just to receive that service, then they missed the entire day of adult day care. So, we are starting to add services in our county.

The CHAIRMAN. What is your relationship with the adult day care center that Mr. Glakas participates in?

Ms. LARMER. I started in that center back in 1979 as the director of that program, and I have seen it expand. When they first opened that center—Fairfax County financially supports that program—it was a program to see if, in fact, it was a needed service, and we opened in January of 1980. Since May of 1980, we have had a long waiting list.

So, the county has opened its second program and is in the planning phase of two more programs.

Now, we are very lucky to live in Fairfax County, because they do financially support the program. We have Title XX funds, and we receive Title III Older American Act funds for the meal component of the program, but the remaining amount is financed through Fairfax County.

The CHAIRMAN. When Mr. Glakas, on the sliding scale that you have in Fairfax County, pays $8 each day he goes, how much of that is subsidized by Fairfax County?

Ms. LARMER. The charge for the participants who pay full fee is $24 dollars. It is going to be increased to $26 this summer.

However, if you include all in-kind services, for example, Fairfax County has renovated elementary schools that were closed, but we pay no rent for that—if you include everything that is in-kind from the county, the cost would be, if we established ourselves as a non-

profit organization that wanted to break even, it would be $37 a day.

The CHAIRMAN. And Senator Burdick asked Mr. and Mrs. Glakas what the professionals are in that particular center.

Ms. LARMER. Yes. We have 1.5 registered nurses, and we have a recreation therapist. We have physical therapy, occupational therapy, and speech therapy available as a consultant for those that need it.

For example, if we had someone come to our center who required physical therapy, it would just be a matter of our picking up the phone and getting them to come in and do an evaluation and provide the care. They are not on-site, but they are an ancillary service, as is podiatry and a variety of other health services, dental services, and so forth.

The CHAIRMAN. All right, the full cost is $37 a day, and there are professionals to assist in each phase from nursing to physical therapy and speech therapy, et cetera. Given that, you have to prioritize this. After all, you are speaking for the National Council on the Aging.

Should this be a major concern, the major concern, given what Congress always has to do is to prioritize what goes on with Medicare and what is available under Medicare. Should this be the number one priority, adult day care centers?

Ms. LARMER. For long-term care? In the whole system of long-term care? If I had to choose?

The CHAIRMAN. Well, consider our position in having to prioritize what Medicare can cover. Is this the number one priority now?

Ms. LARMER. Well, I would like to back up a second, Senator, and talk about CBO's estimates, because I really firmly believe that they do not look at cost off-setting information and that if they did, then I believe that we could look at the whole spectrum of services that are required and, with cost off-setting, be able to see that with adult day care when appropriate, with home care when appropriate, with respite care when appropriate, we would with those packages still provide services at less cost than institutional care.

Now, I know there are lots of people who don't agree with me, but I have difficulty in saying adult day care is the number one priority for NCOA. From a day care director's perspective, I can say that easily, but I think when you look at the broader picture, we need to look at what is best for the older person and their family, and the only way to do that is to provide options for them and to allow them some choices based on their personal needs.

Now, adult day care meets a lot of those needs, and that may be one place to start to develop an in-home care system as well, but some people need in-home care as well. Some people need just respite care. The family just needs four hours a night to get out and be able to do something, but they need to get out of their own home.

There is a variety. I would hope, given the country that we live in, that we can look at this kind of long-term care system and find ways so that our people in our nation have the ability to choose rather than favoring just—I think we have long favored institutional care. I hope we don't do that now with home care or something else. I hope we offer the options that are needed.

The CHAIRMAN. Well, then, perhaps you would like the two or link the three, home care, respite care, and day care. You would link them all together as being the step needed?

Ms. LARMER. As separate services. I think what has happened in some of the bills——

The CHAIRMAN. Yes, I understand, but become part of Medicare.

Ms. LARMER. Yes, and required services.

The CHAIRMAN. And required services?

Ms. LARMER. And they are required services in order to enable someone to stay in their home and community.

The CHAIRMAN. Yes, home health care.

Now, you mentioned three insurance carriers have recognized this as part of what they would provide to their policy holders?

Ms. LARMER. That is correct. They are Prudential through the AARP insurance long-term care plan, Aetna, and Travelers.

The CHAIRMAN. Three of the large ones, then.

Ms. LARMER. Yes. They are currently providing adult day care.

The CHAIRMAN. Thank you.

Senator Bradley.

Senator BRADLEY. Thank you very much, Mr. Chairman.

I would just like to ask Mr. Peterson what he thinks is the standard that providers of adult day care should follow. We are very interested in quality in addition to providing the service.

Do you have any thoughts for the committee on standards that providers of adult day care should adhere to?

Mr. PETERSON. We used NIAD standards to develop our program, and we believe they have come a long way in the development of good standards, and certainly think they could represent a basis for national standards that ensure quality services.

Senator BRADLEY. Ms. Larmer.

Ms. LARMER. The NIAD standards were developed back in 1984 as a result of the fact that there were no standards at all for adult day care. We are in the process now of revising those standards to address the more specialized programs that we see developing in our country, for example, programs that serve only Alzheimers, programs that serve head injured, programs that serve mentally disabled individuals.

We also will accompany these revised standards with a self-assessment tool, but we feel that this is just one step towards quality programs. We would eventually like to see certification be implemented so that programs were certified to be quality programs.

Senator BRADLEY. Certified by?

Ms. LARMER. Well, we would like to see Medicare cover adult day care and then certification would come accompanying the Medicare.

Senator BRADLEY. Thank you.

The CHAIRMAN. Thank you, Senator.

On the standards, when would NIAD have completed this revision of standards?

Ms. LARMER. Well, right now, we are looking for funding to help us with these standards revisions. We have the proposal that we have submitted to—actually, we submitted to the State agencies on aging to help us fund it, and at this point, we don't know exactly

when, but this is our number one priority for this year, and we hope to have it done within a year or so if funds can be obtained.

The CHAIRMAN. Thank you. Thank you both for giving us some excellent testimony and good background.

Mr. PETERSON. Thank you.

The CHAIRMAN. The next witness is Ellen Shillinglaw, Director of the Office of Legislation and Policy for the Health Care Financing Administration.

STATEMENT OF ELLEN SHILLINGLAW, DIRECTOR, OFFICE OF LEGISLATION AND POLICY, HEALTH CARE FINANCING ADMINISTRATION

Ms. SHILLINGLAW. My name is Ellen Shillinglaw, and I am the Director of the Office of Legislation and Policy for the Health Care Financing Administration.

I am pleased to be here this morning to discuss with you the issue of day care for non-institutionalized adults. There are thousands of young as well as elderly adults with serious health impairments being cared for at home who benefit from the extra assistance provided by an adult day care center.

Adult day care centers are designed to afford relief for family care givers, allowing the family members to continue working and attending to the needs of children and other family members.

The Department of Health and Human Services has a key role in funding adult day health care. My statement will focus on a profile of our experience with community based care, including adult day health, and the cost effectiveness of this care.

I will go into some detail later in my testimony about cost effectiveness, but would like to indicate that adult day health care should be viewed, by and large, as additional services to additional clients and not as a substitute for nursing home care.

I would like to begin by offering some background on the clientele and services of adult day care centers.

Adult day care centers vary a great deal in the services they provide to their clientele, but there are similarities in the programs and populations served. The most comprehensive analysis of adult day care is from a 1985 National Council on Aging survey of adult day care centers that found 50,000 Americans are served in some 1,200 adult day care centers.

Most clients of these centers are elderly and physically disabled, and many clients are developmentally disabled, mentally retarded, or mentally ill. The average participant in adult day care is a 73-year-old, white female with a monthly income of $478. She lives with a spouse, relatives, or friends, and she attends the center for 6 hours 2 to 3 days a week.

The typical center is open Monday through Friday for 8 or more hours a day and has 37 participants. It provides a variety of services such as nursing, nutritional services, counseling, and transportation.

The largest single funding source of adult day care is the Medicaid program, but centers do rely on a variety of funding mechanisms. Medicaid permits coverage of these services primarily through home and community based waiver programs. However,

States may choose to provide them through clinic, rehabilitation, or outpatient service options.

There are 31 States which operate 47 home and community-based care waivers that include adult day health as a part of a program to avoid institutionalization. Between 1985 and 1987, these programs spent $28.4 million specifically on adult day care services.

For example, a Minnesota waiver pays $8,916 per person per year for community-based services which include adult day care. Institutional care would cost approximately $10,000. In a Rhode Island program, community care runs $7,393 per year compared to $8,050.

Although these numbers indicate that annual community-based care costs per client are less than nursing home costs, it is important that one not reach the conclusion that such care is cost effective in the aggregate.

The Department has initiated two kinds of demonstrations which contribute to our understanding of the cost effectiveness of adult day care and its capacity to substitute for nursing home care. One tested the cost effectiveness of community care, including adult day care. The other looked specifically at adult day care programs.

The first includes over 15 years of experience in operating case management and community-based care demonstrations intended to provide cost-effective care to the frail elderly. The largest of these initiatives are the Channeling Demonstration and the recently completed evaluation of the home and community-based waivers program under Medicaid.

In 1980, the long-term care Channeling Demonstration program was launched to test whether a carefully managed approach to the provision of community-based long-term care could control overall long-term care costs for frail elderly individuals who were at risk of being placed in nursing homes.

Under this study, over 6,000 individuals received expanded in-home and community-based services including day care services. While these services reduced unmet needs and improved client and informal caregiver satisfaction, they did not result in substantial reductions in nursing home use, even though the targeted group was made up of extremely frail individuals.

In fact, the rate of institutionalization of the demonstration group and the control group were virtually identical and relatively low, about 13 percent at the end of the first year.

In a recent comprehensive review of the Department's community care demonstration experience, the National Center for Health Services Research reports that the populations served by these demonstrations turned out to be at relatively low risk of nursing home placement, precluding large reductions in nursing home use.

In short, our work has repeatedly shown that expanding publicly financed community care does not reduce aggregate costs. In fact, it dramatically increases costs.

We looked at the cost effectiveness of adult day care as a more discrete service in at least three studies, the adult day care homemaker experiments, the Georgia Health Alternative Project, and On Lok in California.

The results of these studies largely confirm the previous findings, that the populations served turned out to be at low risk of nursing

home placements, so costs increased. The exception is the On Lok program where day care is the core of the service package.

While On Lok results do suggest that day care can be cost effective, this demonstration has some unique features which make it quite different from the others. On Lok was able to authorize the full continuum of physician, hospital, and nursing home care, making it look much more like an HMO than a typical community care program. Because of these unique characteristics, its findings may not be able to be replicated in other situations.

Our community care and adult day care demonstrations have identified some very positive benefits to participants: Increased independence for the impaired person and valuable support for their family caregivers. However, these benefits do end up costing additional money since, as research has consistently shown, adult day care does not offset nursing home costs.

Thank you very much. I will be happy to answer any questions you may have.

[The prepared statement of Ms. Shillinglaw follows:]

DEPARTMENT OF HEALTH & HUMAN SERVICES

Health Care Financing Administration

Washington, D.C. 20201

STATEMENT OF

MS. ELLEN SHILLINGLAW

DIRECTOR

OFFICE OF LEGISLATION AND POLICY

HEALTH CARE FINANCING ADMINISTRATION

BEFORE THE

SENATE SPECIAL COMMITTEE ON AGING

APRIL 18, 1988

Mr. Chairman and Members of the Committee, I am Ellen Shillinglaw, Director of the Health Care Financing Administration's (HCFA's) Office of Legislation and Policy.

I am pleased to be here this morning to discuss with you the important issue of day care for noninstitutionalized adults. There are thousands of young as well as elderly adults with serious health impairments being cared for at home who need the extra assistance provided by an adult day care center. Adult day care centers are designed to afford relief for family caregivers -- allowing the family members to continue working and attending to the needs of children and other family members.

The Department of Health and Human Services has a key role in funding adult day health care. My statement will focus on a profile of our experience with community-based care including adult day health care and the cost effectiveness of this care.

I would like to begin by offering some background on the clientele and services of adult day care centers. Adult day care centers vary a great deal in the services they provide to their clientele, but there are similarities in the programs and populations served. The most comprehensive analysis of adult day care is from a 1985 National Council on the Aging and National Institute on Adult Daycare survey of adult day care centers that found:

- 50,000 Americans are served in some 1,200 adult day care centers -- six times the number of centers only ten years ago;
- most clients of these centers are elderly and physically disabled;
- many clients are developmentally disabled, mentally retarded, or mentally ill;
- one in thirteen clients is incontinent;
- nearly half are cognitively impaired, and one in five is so cognitively impaired that constant supervision is needed;
- one in eight is in a wheelchair and one in five relies on a walker or a cane to get around.

The average participant in adult day care is a 73 year old white, female with a monthly income of $478. She lives with a spouse, relatives or friends. She may be Medicaid eligible since a reported 43 percent of participants are Medicaid recipients.

The average adult day care center client attends the center for six hours, two to three days per week. The typical center is open Monday through Friday for eight or more and has 37 participants.

The centers generally provide a variety of services such as nursing, nutritional services, counseling, personal care, reality therapy, exercise, social services, and transportation to and from the center. Staffing varies according to the types of services offered, but may include physicians, nurses, or social workers. Volunteers play an important role in the functioning of these centers. Most centers rely on funding from a number of sources including Federal, State, and local governments; private insurance; foundations; and donations.

In the National Council on the Aging's survey, centers indicated that their major source of funding is the Medicaid program. Participant fees are next, followed by Department of Health and Human Services' Social Services Block Grant program. There were various additional sources of funding, including HHS' Administration on Aging, private donations, and State dollars.

The largest single funding source of adult day health care, the Medicaid program, permits coverage of these services primarily through home and community-based waiver programs. However, States may choose to provide them through clinic, rehabilitation, or outpatient services.

Thirty-one States operate 47 home and community-based care waivers that include adult day health as part of a program to avoid institutionalization. Between 1985 and 1987 these programs spent $28.4 million specifically on adult day care services.

For example, a Minnesota waiver pays $8,916 per person per year for community-based services which includes adult day care. Institutional care would cost $10,135. In a Rhode Island program, community care runs $7,393 per year compared to $8,050 for institutional care. In Montana, the costs are $9,371 in the community and $10,296 in the institution. Although these numbers indicate that annual community-based care costs per client are less than nursing home costs, it is important that one not reach the conclusion that such care is cost effective in the aggregate.

The Department has initiated two kinds of demonstrations which contribute to our understanding of the cost effectiveness of adult day care and its capacity to substitute for nursing home care. One tested the cost effectiveness of community care -- including adult day care. The other looked specifically at adult day care programs.

The first set of studies includes over 15 years of experience in operating case management and community-based care demonstrations intended to provide cost-effective care to the frail elderly. The largest of these initiatives are the Channeling Demonstration and the recently completed evaluation of the home and community-based waivers program under Medicaid.

In 1980, the National Long Term Care Channeling Demonstration Program was launched to test whether a carefully managed approach to the provision of community-based long term care could control overall long term care costs for frail elderly individuals who were at risk of being placed in nursing homes.

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Under this study, over 6,000 individuals received expanded in-home and community-based services including day care services. While these services reduced unmet needs and improved client and informal caregiver satisfaction, they did not result in substantial reductions in nursing-home use, even though the targeted group was made up of extremely frail individuals. In fact, the rate of institutionalization of the demonstration group and the control group were virtually identical and relatively low -- about 13 percent at the end of the first year.

These findings have been more recently confirmed by the results of detailed case studies associated with the home and community-based waiver evaluation which also found low rates of nursing home use among the treatment and comparison groups.

In a recent and comprehensive review of the Department's Community Care Demonstration experience, the National Center of Health Services Research reports that the populations served by these demonstrations turned out to be at relatively low risk of nursing home placement, precluding large reductions in nursing home use. In short, our work has repeatedly shown that expanding publicly financed community care does not reduce aggregate costs -- in fact it dramatically increases these costs, because they are not offset by nursing home reductions.

In addition to these more comprehensive community care demonstrations, we have looked at the cost effectiveness of adult day care as a more discrete service in at least three studies: the Adult Day Care/Homemaker experiments; the Georgia Health Alternative Project and On Lok.

The results of these studies largely confirm the previous findings, that the populations served turned out to be at low risk of nursing home placements, so costs increased. The exception is the On Lok program where day care is the core of the service package. While On Lok results do suggest that day care can be cost effective, this demonstration has some unique features which make it quite different from the others. On Lok was able to authorize the full continuum of physician, hospital

and nursing home care making it more like an HMO than a typical community care program. Because of these unique characteristics, its findings may not be able to be replicated in other situations.

Our community care and adult day care demonstrations have identified some very positive benefits to the participants. There was increased independence among adult day care users that was not experienced by those in the control group who did not attend adult day care. Some participants were able to dress themselves again and others learned to administer their insulin. Families were also helped to cope with stress and to accept their relatives' disabilities. Participants experienced improvements in quality of life measures and increased satisfaction.

Adult day care does offer valuable support to impaired people and their family caregivers. However, these benefits do end up costing additional money since research has consistently shown that adult day care does not offset nursing home costs.

Thank you very much. I will be happy to answer any questions that you may have.

The CHAIRMAN. Well, I think it would be fair to say at the outset, Ms. Shillinglaw, that the testimony previously given and everything I have been able to ferret out on this subject contradicts your statement and that nursing home costs would indeed be reduced and, in fact, are currently reduced simply because of adult day care centers.

However, let me go back through your testimony and find if I can be edified by the facts you presented.

First, you say that 50,000 Americans are served in some 1,200 adult day care centers. Information we have is that it is 66,000. Both sound rather low, but there is a great disparity percentagewise between 50,000 and 66,000.

What is the difference?

Ms. SHILLINGLAW. The numbers that we were citing were from a study not that we did but by the National Council on Aging.

The CHAIRMAN. When did they do that study?

Ms. SHILLINGLAW. 1985. To the extent——

The CHAIRMAN. Well, this is 1988, and your testimony is that it is 50,000 today. Would the 66,000 sound more accurate to you?

Ms. SHILLINGLAW. It may well be if those are more current statistics. I would point out that our primary relationship with adult day health centers is through the Medicaid program. Since these are home and community-based waivers, we don't have very good statistics on how many people are participating in that specific kind of program because they are run by States.

So, there is some lack of data.

The CHAIRMAN. Well, then the next figure in the same line is 1,200 adult day care centers, and my information is that there are 1,400, again, a significant difference. Is this all due to lack of up to date data or what?

Ms. SHILLINGLAW. Some, yes, and it is an increasing kind of service, so it would be reasonable to expect that new adult day care centers would be opening.

The CHAIRMAN. I find it disconcerting, at least to me, that you are giving this testimony as if it is today and it is based on something that occurred in 1985.

Ms. SHILLINGLAW. We used the best information we had available to us in the testimony.

The CHAIRMAN. Well, you don't cite that it is based on a 1985 study.

Since Medicaid—maybe I shouldn't rely on your figures, but you state that Medicaid provides most of the funding. I suspect that is still true. Is that right?

Ms. SHILLINGLAW. HCFA provides a bulk of the funding for adult day health care, but there are other department programs which also fund adult day care. That would be the Older Americans Act, the Title XX Block Grant—there are other government programs outside of our department that provide adult day health care.

So, I believe I remember a figure of approximately 23 percent of the funding is Medicaid funding, but it again would depend on the type of adult day care center as to what sources of funding they use, which in turn would define the kind of services they offer.

The CHAIRMAN. Yes, I think Ms. Larmer said that Fairfax County used both of the Federal programs for partial funding of

their program and then put in a big chunk of the money for adult day care centers.

When you speak of a Minnesota waiver pays $8,900 per person per year for community based services which includes adult day care centers and then you say that institutional care would cost $10,135, tell me what you mean by institutional care?

Ms. SHILLINGLAW. Because these programs are funded under home and community based waivers, the States give us a plan that demonstrates that the home and community based waiver will cost less than if these persons were in institutions. So, in the Minnesota waiver, for example, they estimate that the Federal and State cost of paying for someone in a nursing home would have been approximately $10,000.

Under the waiver, they would like to provide a range of services to the eligible population in the community as opposed to in the institution and they estimate that the Federal and State cost would be approximately $8,000 to provide that kind of service outside the institution.

So, it would be a question of paying institutional bills as opposed to community care.

The CHAIRMAN. Well, let's start with the $8,900 figure. If it were an adult day care center that would keep somebody out of a nursing home, we are talking about $40 times 31 if that is the average or, take Fairfax at $37 which is over 200 days would be less than $8,000, wouldn't it?

Ms. SHILLINGLAW. Yes.

The CHAIRMAN. So, what you have done here—you are really not breaking out adult day care centers.

Ms. SHILLINGLAW. No, in the waivers, it is difficult for us to break out the actual cost of the adult day care portion of the whole home and community-based waiver. So, for the purposes of demonstrating community-based care as opposed to institutional care, that is the $8,000 figure.

How much we are spending for an adult day care population in a particular waiver State is information that is very difficult for us to isolate.

The CHAIRMAN. But on a Medicaid case, if the adult day care center would keep some Medicaid case from being in a nursing home—I hate to even sound this impersonal—some individual who without adequate funding has to rely on Medicaid for health care, if we just consider that individual, aren't we talking about $20,000 per year?

Ms. SHILLINGLAW. Intuitively, it makes sense that if adult day care services did keep people from institutions, it would result in savings. The problem is that in all of the work that we have done to date, we find that the people who are participants in adult day care centers were not likely to go into a nursing home anyway.

So, you have adult day care services supplanting the kind of family services that families had provided and adding additional medical services and not necessarily keeping them from going into institutions. Obviously, there are some participants who are helped and who don't have to go into an institution.

But the studies so far don't document that on a large scale.

The CHAIRMAN. Well, I don't know what study, though, because you don't have any studies. You use the National Council on Aging for a 1985 study which really doesn't zero in on the point.

When we are talking about Federal dollars, what would be the Federal dollar portion of a person covered by Medicaid in Minnesota that is in a nursing home at a cost of $20,000 per year?

Ms. SHILLINGLAW. I don't know off the top of my head what the Medicaid matching rate in Minnesota is. We have a variety of matching rates depending on the State. They tend to average about 50 percent, so whatever Minnesota's matching rate is, we would match dollar for dollar if it is around 50 percent matching.

The CHAIRMAN. But somebody saves a great deal of money here, and we are trying to arrive at a Federal dollar savings. You can't find much, but I would think that the difference, even with your own figures, is substantial.

Ms. SHILLINGLAW. With home and community based waivers.

The CHAIRMAN. That is right.

Ms. SHILLINGLAW. Yes.

The CHAIRMAN. But the reason you say that isn't so important is because you don't believe that the people who are assisted at adult day care centers would be in nursing homes in any case.

Ms. SHILLINGLAW. We have had some problems successfully identifying how to target the home and community-based waiver programs for adult day care, how you figure out which of the elderly really are going to be going into nursing homes and, therefore, how you could demonstrate the cost effectiveness.

To the extent that you are providing services to people who would not go into a nursing home anyway, you can't document savings.

The CHAIRMAN. The only figures you have, then, are the basis of whatever the States submit as waivers and the National Council on Aging study of 1985.

Ms. SHILLINGLAW. Yes, we have some additional studies that we would be happy to respond about in writing. We have one that the Urban Institute did. We have one that was done in Berkeley, and we have the Channeling study.

The CHAIRMAN. Well, there are two facets to this. Can we improve the quality of life, and the preponderance of testimony we have heard and whatever we can sort out from what we have read prior to these hearings is that it does improve the quality of life in a gigantic step forward. You would agree with that, would you not?

Ms. SHILLINGLAW. We do know that there are some positive benefits with people who are able to do more for themselves—

The CHAIRMAN. I would like a little more definitive answer than that. Either you agree or you have some reservations. You can state it that way if you have reservations, but I am asking it again.

Does not all the evidence indicate that adult day care centers improve the quality of life for those that go there in a gigantic way? Now, if you have reservations, say so, and if you agree, say yes.

Ms. SHILLINGLAW. I have reservations about gigantic, but it clearly improves their mental outlook on life for some of them and——

The CHAIRMAN. I would call that gigantic. Some of them? That is a reservation.

I find that I can't agree with your conclusions. That is one point. But I also find that I am a little bit dissatisfied that you haven't really delved into this enough to give more either positive answers or, if they are not positive, factual answers that would be credible.

The CBO gets its figures on projecting costs from you, does it not?

Ms. SHILLINGLAW. They have their own data bases for——

The CHAIRMAN. Don't they base those data bases on your experiences primarily?

Ms. SHILLINGLAW. I couldn't address their Medicaid data base. Again, the frustration that you are feeling is the fact that the Medicaid programs are run by the States. To the extent that States decide what kind of services and to what groups they are going to offer those services, at the Federal level, we have limited amount of data about what kind of——

The CHAIRMAN. Well, I can accept that. I would draw that same conclusion on Medicaid, but what bothers me is how to keep people off of Medicaid. How do our previous witnesses, Mr. and Mrs. Glakas, stay off of Medicaid without adult day care centers?

That is what we would expect from you, and we don't seem to be getting it. I can accept the Medicaid part as you demonstrated here as gathering data from the States, but I simply accept that portion of it as a Federal cost. Somebody has to pay that cost between what adult day care centers or home health care provides and being in a nursing home, but I would think that how to avoid Medicaid would be of big interest to HCFA, and that is what I find lacking in your testimony.

Thank you.

Senator Bradley.

Senator BRADLEY. Mr. Chairman, thank you very much.

Let me say that you have covered many of the topics that I was to have covered. I will say a good word for Ms. Shillinglaw. She has, over the years, demonstrated a real sensitivity to these kinds of issues both in her work on the Finance Committee and also where she is now.

So, I hope she will help us to try to get the data base that we need to make what we think is the right case.

With that in mind, would you support, Ellen, the provision in the catastrophic health care bill to study existing adult day care centers?

Ms. SHILLINGLAW. Absolutely. It is in the Senate bill, and we have supported the Senate bill, and there is a study in there.

Senator BRADLEY. What has HCFA or the Federal Government issued in the way of informational pamphlets for care givers on where to find adult day care centers?

Ms. SHILLINGLAW. That would come, if it comes at all, primarily through the Administration on Aging. The Health Care Financing Administration is really a payor of services and a payor of services that States run.

To the extent that the Older Americans Act and the Administration on Aging have ombudsman services and they are funded to provide information to the elderly, one assumes that part of the information that they give out is locations of adult day care centers,

and I know that they fund adult day care programs in some States. So, they would have that kind of information.

Senator BRADLEY. Could you obtain that and provide it for the record, please?

Ms. SHILLINGLAW. Indeed.

[Subsequent to the hearing, the following information was received for the record:]

A critical component of the Administration on Aging's (AoA) efforts to develop comprehensive and coordinated systems of service at the community level is the dissemination of the a guidebook for caregivers, "Where To Turn For Help For Older Persons: A Guide for Action on Behalf of an Older Person" (see attachment A). This generic booklet is designed to enable family caregivers, neighbors and friends of older persons to find help when it is urgently needed by identifying frequently asked questions about the special needs of vulnerable older persons. On page 21 of the caregivers' guide, the section on available community services discusses Adult Day Care Services. The guide explains that adult day care services provide social and some rehabilitative activities for the frail older person during the day in a community facility. The caregivers' guide also provides the telephone number of the relevant State Agency on Aging and refers persons interested in securing more information about adult day care to that agency which, in turn, will refer the individual to the appropriate area agency on aging at the community level. Information and referral about adult day care and other long-term care services are two of the essential activities for which area agencies on aging are responsible. Over 300,000 copies of the caregivers' guide have been reprinted by non-Federal sources. The caregivers' guide is currently being updated.

The Administration on Aging has also issued a Long-Term Care Ombudsman Program Technical Assistance Manual. This manual has been distributed to all State and area agencies on aging. Chapter II of the manual discusses the spectrum of ombudsman responsibilities which are based upon the requirements of the Older Americans Act, as amended. These responsibilities include providing information to the public about adult day care and other long-term care services. Chapter XI of the manual discusses training for ombudsman program staff and volunteers. Ombudsman training provides basic reference information about adult day care and other out-of-institution services. This training makes clear that these services are an important component of the long-term care continuum which ranges from the provision of community-based health or social services to full institutionalization.

In addition, AoA is undertaking collaborative efforts with other organizations and has entered into a private-public partnership with the Robert Wood Johnson Foundation (RWJF). This joint undertaking will pool resources in order to support projects intended to develop day care programs and other respite and health-related services needed by the victims of dementia as well as their caregivers. It is anticipated that AoA will co-fund up to nine (9) projects with RWJF for a total cost of $625,000 in FY 1988.

Finally, another excellent source of information about adult day care (see attachment B) is from the National Institute on Adult Daycare (NIAD). NIAD is a membership unit of the National Council on Aging (NCOA) - 600 Maryland Avenue SW Washington, D.C. 20024 (202) 479-1200.

Where to Turn for Help for Older Persons

A Guide for Action on Behalf of An Older Person

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Office of Human Development Services
Administration on Aging

We encourage photocopying or reprinting this information

Preface

This booklet is designed to assist you in finding help when you are faced with an *urgent situation* regarding an *elderly* family member, friend or neighbor. Keep this booklet in a place where you can find it for a quick reference when needed.

Often a crisis occurs for an older loved one who lives in a community other than the one in which you live—across the State, or across the nation. The information in this booklet is designed to provide you with guidance as to where to find help in the community where the older person lives.

The first section of this guide contains the most frequently asked questions or issues in the most significant life areas.

Become familiar with this booklet, and learn how to use it. It may make all the difference in a crisis for an older person that you care a great deal about!

Carol Fraser Fisk
U.S. Commissioner on Aging

User's Guide

Throughout this booklet there are references to the local **Area Agency on Aging**. These are local agencies designated by the Governor of each State to be concerned with all matters that relate to the needs of the elderly in the community. It is this agency that is most likely to be able to mobilize help in time of need in the community in which an older person lives.

Because of the large number of these local agencies around the nation, it is impractical to provide accurate addresses and telephone numbers in this booklet. Rather, you will be directed to the **State Agency on Aging** charged with managing these agencies. You only need to ask for the **Area Agency on Aging** responsible for the community or county in which the older person lives. The **State Agency** will supply you with the telephone number of the local agency.

You should then call the appropriate **Area Agency on Aging**. They will help you.

Need Help?

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Need Help?

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Need Help? *(Continued)*

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Need more information? Call the **State Agency on Aging**	37	

FINANCES

1. Programs Under the Older Americans Act

There are a variety of services funded by the Older Americans Act which are available in each community through the **Area Agency on Aging.** These services, which are available to all older persons, include information and referral, homemaker/home health-aides, transportation, congregate and home delivered meals, chore and other supportive services. Contributions are encouraged; however, there is no fee for services under Older Americans Act programs. The types of services available vary in each community based upon the needs and resources of a given locality. Contact the **Area Agency on Aging** for information about obtaining these services.*

2. Social Security

Social Security is a national retirement income supplement available to nine out of ten Americans over 65 years of age (persons age 62 may qualify under certain conditions). Monthly benefits are available to workers upon retirement, to their dependents and/or survivors, and to the severely disabled.

Individuals who wish to apply for Social Security may write or telephone the local Social Security office for instructions on how

*See page 37 for the telephone number of the agency to help you.

to file a claim at least three months before becoming eligible for benefits. Spouses and widows/widowers may be eligible for special benefits, including death benefits. Individuals who are disabled before 65 may apply for Social Security disability benefits.

Older persons may have their Social Security checks sent directly to their bank by the United States Government. This prevents lost or stolen checks and eliminates a trip to the bank to deposit the check. Contact your local Social Security Office for information about direct deposit and ask your bank about this service.

3. Supplemental Security Income (SSI)

Supplemental Security Income (SSI) assures a minimum monthly income to needy persons with limited income and resources, who are 65, blind or disabled. Eligibility is based on income and assets. Local Social Security offices take applications, help file claims and provide information about the programs.*

4. Medicare

Medicare is a Federal health insurance program which helps defray many of the medical expenses of most Americans over the age of 65. Persons eligible for Social Security may also apply for Medicare benefits.

*See page 37 for the telephone number of the agency to help you.

Older persons should apply for Medicare benefits three months prior to the 65th birthday. For information about how to apply for Medicare, telephone or contact the local Social Security office. Working persons over 65 are entitled to Medicare even though they do not apply for Social Security.

Medicare has two parts:

A. *Part A—Hospital Insurance*—Medicare Part A helps pay the cost of inpatient hospital care. In some instances, and under certain conditions, Part A helps pay for inpatient care in a skilled nursing facility, home health care and hospice care.

Older persons and their families need to be knowledgeable about Medicare coverage. Detailed information about Medicare benefits, including a number of pamphlets explaining coverage can be obtained from the local Social Security Office.

It is important that older persons and their families understand patients' rights under Medicare. Written material describing these rights should be provided to patients upon admission to a hospital. This is especially true since the number of days in the hospital paid for by Medicare is governed by a system based upon patient diagnosis and medical necessity for hospital care. Once it has been determined that it is no longer medically necessary for the older person to remain in

the hospital, the physician will start the discharge process.

If the older person or the family disagrees with the decision to discharge the patient, the decision may be appealed. To initiate an appeal, the State's Peer Review Organization (PRO) must be contacted by the patient or the family. Each hospital has the name, address and telephone number for the PRO responsible for overseeing hospital inpatient services. Information about how to contact the PRO is available from the hospital administrator's office, social services or business office staff. The patient or family can obtain information about implementing appeal procedures from the PRO and should ask about time limits governing these procedures.

B. *Part B—Medical Insurance*—Part B helps pay for medically necessary doctors' services, outpatient hospital services and some other medical services. Enrollees must pay a monthly premium for Part B. Inquire at your local Social Security office for more information.

Medicare will pay for many health care services but not all of them. Medicare does not cover custodial care or care that is not determined to be reasonable and necessary for the diagnosis or treatment of an illness or injury. In some instances, Medicare may pay for certain psychiatric services. Individuals should check with the local Social Security of-

fice to learn which services are covered.

It is possible to privately purchase supplemental health insurance. This is sometimes referred to as "Medigap." Before purchasing a policy, care should be taken to assure that the plan provides the coverage that the older person wants and needs.

5. Medicaid

Medicaid is a health care program for low income persons cooperatively financed by Federal and State governments. Administered by States, the program provides for medical services to eligible individuals. Benefits cover both institutional and outpatient services. However, the types of services covered may differ from State to State. For example, some States may provide psychiatric services for persons over 65. Each State has a set of criteria that establishes eligibility for services under this program.

Further information about the Medicaid Program is available at the local county welfare, health or social service departments or the Area Agency on Aging.*

6. Other Types of Public Supported Programs

Other sources of public support include food stamps, Veteran's benefits, housing assistance

*See page 37 for the telephone number of the agency to help you.

and low income energy assistance for eligible older persons.

Veterans, their widows or widowers, or parents of veterans with limited income may be eligible for benefits. Contact the local Veterans Administration for the details.

Older persons must apply in order to participate in any of the programs described above.*

7. Private Resources

Families need to determine whether an older person has accumulated private resources which can be used to help pay for the cost of care. These resources may include retirement plans, long term care insurance, equity in a home, Certificates of Deposit (CDs) and Individual Retirement Accounts (IRAs) as well as assistance from family members.

8. Home Equity Conversion

Home equity conversion is a program which enables the owner to utilize the equity in a home for purchase of needed services. Some banks participate in this type of program and will arrange to free up these often overlooked resources to help cover the costs of services needed by the older person.*

*See page 37 for the telephone number of the agency to help you.

9. Property Tax Exemption and/or Deferrals

Property tax exemption and/or deferrals are available in some communities to persons over 65 who have a limited income. Contact the local tax office for more information.

10. Tax Benefits

There are a variety of Federal, State or local tax benefits available to older persons. Contact the Internal Revenue Service, State and local tax offices for further information.

11. Senior Citizens Benefits

Many communities offer special discounts for goods and services to their senior citizens. Reduced prices may be offered through discounts on prescription drugs, transportation services, restaurant meals, recreation facilities, bank services and many other services.*

*See page 37 for the telephone number of the agency to help you.

Health Services

1. Health/Medical Services

Good health care is a very important factor in remaining as independent as possible. Health care, diagnostic and medical services can be obtained through a private physician. When necessary, the family physician can make referrals to a specialist, a hospital or other health services. In some communities doctors will make house calls.

Another approach to receiving health care and medical services is through membership in a Health Maintenance Organization (HMO). Contrary to a fee-for-services approach, HMOs provide care for a predetermined, fixed fee. The patient has a physician who provides and monitors care and, through the HMO, arranges for any additional health care, diagnostic and/or medical services that may be needed. A patient enrolled in an HMO plan must use the doctors and health care facilities covered by the HMO plan or must pay for medical services received outside the plan. Neither the HMO nor Medicare will pay the cost of services rendered by other physicians or facilities except in an emergency situation.

Other types of health care services that many communities offer include educational programs about good health habits, physical fitness, proper nutrition, screening programs for cancer, high blood pressure, diabetes, dental, vision and hearing problems, rehabilitation programs, and programs that monitor the status of chronic physical conditions.

Older persons and their families need to take an active role in selecting the most suitable facility and service to meet the needs of the older persons.*

2. Health/Psychiatric Services

Good mental health is an important factor in remaining independent for as long as possible. Mental health care and diagnostic services may be obtained through private means such as psychiatrists and psychotherapists. Other mental health professionals, such as psychiatric nurses and social workers provide help with emotional problems. Services may also be obtained through the local Community Mental Health Center, psychiatric hospitals, and at some community hospitals.*

3. Hospital/Emergency Services

Many older persons, at some point in time, may require acute care services such as hospitalization and/or emergency medical services. Physical and mental health services are usually obtained through the family physician or the Health Maintenance Organization. If a physician is not available, the patient may be taken to the emergency room of the local hospital. Ambulance services are available in most communities if the patient cannot be taken to an emergency room by any other means.

*See page 37 for the telephone number of the agency to help you.

Soon after a person is admitted to a hospital, the patient and family should be contacted by the discharge planner or social worker. If such contact is not made, inquiries should be made about discharge planning. Plans for the care of the patient, after discharge from the hospital, should be made as early as possible. Older patients and their families should be knowledgeable about Medicare coverage of hospital costs and patients' rights under Medicare. More detailed information about Medicare benefits and patients' rights is provided in the Finances section under Medicare. (See page 2.)*

4. Hospice

Hospice programs provide support and care for terminally ill persons and their families in the last stages of disease. These services, which include pain relief, symptom management and supportive services, are provided in the home with arrangements for inpatient care when needed.*

5. Nursing Home Care

Most older persons continue to live independently throughout all or most of their lives. For older persons who may need assistance, families are often able to provide the

*See page 37 for the telephone number of the agency to help you.

physical and emotional supports that are needed. However, in some cases when family supports are either not available or needs exceed what families can provide, it becomes necessary for the older person to move into a nursing home.

Different nursing homes offer different levels of care. The types of nursing homes include:

A. ***A Skilled Nursing Facility (SNF)***—is a nursing home which provides 24 hour-a-day nursing services for a person who has serious health care needs but does not require the intense level of care provided in a hospital. Rehabilitation services may also be provided. Many of these facilities are Federally certified, which means they may participate in the Medicare or Medicaid programs.

B. ***An Intermediate Care Facility (ICF)***—is also a nursing home which is generally Federally certified in order to participate in the Medicaid program. It provides less extensive health care than a SNF. Nursing and rehabilitation services are provided in some of these facilities, but not on a 24 hour-a-day basis. These homes are designed for persons who can no longer live alone but need a minimum of medical supervision or assistance and help with personal and/or social care.

C. ***Board and Care Facilities***—provide shelter, supervision and care, but do not offer

medical or skilled nursing services. Unlike the SNF and ICF facilities, board and care facilities are not licensed to receive reimbursement under Medicare and Medicaid programs. In some States, the residents of board and care facilities may receive financial assistance through a State supplement to the individual's Supplemental Security Income (SSI) payment.*

D. ***Choosing a facility***

☐ *Advance planning*

It is best to anticipate ahead of time that an elderly relative may need nursing home care. It is important for the older person to participate in the decision making process whenever possible. Early planning allows time for full exploration of the options available and will improve the chances of making appropriate decisions at the most appropriate time.

Three primary factors affecting the choice of a nursing home are the type of care required, the financial resources available and the convenience of location. In many States, pre-admission screening is required prior to admission to a nursing home. Information about choosing a nursing home can be obtained from the Area Agency on Aging in the area, information and referral agencies, local

*See page 37 for the telephone number of the agency to help you.

social service agencies, the Nursing Home Ombudsman, doctors, nurses, social workers, hospital discharge planners, clergy, friends or other families who have relatives in a nursing home. In addition, there are a number of publications available on nursing homes which may be found in a public library or book store.*

The first consideration in selecting a nursing home is to ensure that the facility can provide the type of care needed. Questions about what care may be needed should be discussed with the older person's physician.

The second prime factor is a frank analysis of the older person's financial status. There should be a complete inventory of available resources. This includes: source and level of income, property, savings accounts, stocks and bonds, veteran's benefits, pension provisions, insurance benefits and any family assistance available. If the older person can not afford to pay for nursing home care, hospital or local social services departments will provide information about eligibility requirements and procedures for applying for assistance from publicly financed programs. If an older person is unable to pay for nursing home care, the choice of a nursing home is limited to a facility which accepts Medicaid and has an opening.

*See page 37 for the telephone number of the agency to help you.

The third factor is to decide on the best geographic location. The best choice is a facility which is most convenient to family and friends.*

☐ *Emergency Placement*

Many older persons and their families delay or avoid discussions and decisions about nursing home placement until failing health forces an immediate decision. If immediate help is needed in locating a nursing home or determining the quality of care provided in a particular facility, contact the Area Agency on Aging for assistance. Additional valuable information can be obtained through consultation with the physician, hospital discharge planner, State or local Nursing Home Ombudsman, local Social Security office, clergy and families of other nursing home residents.

Emergency placement in a nursing home is necessary in some instances if an older person is required to transfer from the hospital to a nursing home on short notice. Even under these circumstances, appropriate timing and arrangements for this transfer should be discussed with the physician and hospital personnel.

Even though the need for nursing home placement is urgent, it is still essential to consider the type of care needed, the finances

*See page 37 for the telephone number of the agency to help you.

available and the convenience of the facility's location.

E. ***Nursing Home Ombudsman***—The best way for families to assure quality care for an elderly relative in a nursing home is for family members and friends to continue to be involved with the older person through frequent visiting and good communication with the nursing home staff. If a question or problem arises regarding care of the nursing home resident, the first step in resolving the issue is to talk to the nursing staff or the social worker. If the issue continues to be of concern, the next step is to talk to the nursing home administrator. If these steps do not resolve the issue, the resident and/or the family may want to contact the Nursing Home Ombudsman who serves the community. The Ombudsman works with nursing home residents and families to negotiate a satisfactory resolution to questions and/or problems which have surfaced.

All States and many local communities have an Ombudsman who is responsible for investigating and resolving complaints made by or on behalf of residents in long term care facilities. The Ombudsman monitors the implementation of Federal, State and local laws governing long term care facilities. In many

*See page 37 for the telephone number of the agency to help you.

areas, the Ombudsman sponsors and encourages the development of local citizen groups to promote quality care in long term care facilities.*

F. ***Patients' Rights***—Persons entering a nursing home continue to have the same civil and property rights as they had before entering the home. Nursing homes participating in the Medicaid and Medicare programs must have established patients' rights policies. Ask the nursing home for a copy of its patients' rights policies. Contact the Nursing Home Ombudsman program for more information. The Ombudsman can be reached through the **State Agency on Aging**.*

*See page 37 for the telephone number of the agency to help you.

COMMUNITY SERVICES

Community Services

1. Information and Referral
Most communities have agencies whose primary function is to provide people with information about where to go for the help they may need. If this type of assistance is required, a local **Area Agency on Aging** can help.*

2. Emergencies
Each community has an emergency number to dial in time of crisis. Check the telephone book or call the information operator for this number. It is helpful to post this number on each telephone for quick use in times of crisis.*

3. Transportation
There are services that can help in getting around in the community. A number of communities offer door-to-door transportation services for older persons such as vans or mini-buses which accommodate wheelchairs, walkers and other devices. Transportation may be provided to and from the doctor's office or other medical services; community facilities and other services.

Help may also be available in the form of escort services and shopping assistance.*

4. In-Home Health and Personal Care
Some older people may need help in the home

*See page 37 for the telephone number of the agency to help you.

with health care, such as taking medications, changing dressings, catheter care or other skilled nursing services. Others may need assistance with their personal care in the areas of bathing, dressing and grooming. Many communities have home health agencies that provide appropriate, supervised personnel to help older persons with both types of care.*

5. Homemaking, Home Maintenance and Chore Services
Services exist in many communities that help older persons with such activities as:

- light housekeeping
- laundry
- shopping
- errands
- meal preparation
- home improvement or maintenance
- heavy cleaning
- yard and walk maintenance.*

6. Home Improvement/Weatherization
Limited home improvement grants and/or loans are available to older persons who meet income eligibility guidelines under a federal block grant program. Funds can be used for roofing, ramps, and insulation.*

*See page 37 for the telephone number of the agency to help you.

7. Medical Equipment
Purchasing or renting medical equipment may become a necessity. In some cases, when ordered by a physician, rental or purchase of medical equipment is covered by Medicare or Medicaid. Some communities supply medical equipment through local voluntary agencies. In addition to the local **Area Agency on Aging**, the local health department may provide more information.*

8. Nutrition/Meals
Each **Area Agency on Aging** has information about group and home delivered meals that are available to older persons in the community. These programs help people maintain an adequate diet by providing a nutritious meal daily.*

9. Respite Care
There are ways that a relative can be relieved of caregiving duties for a short period of time. Some communities offer volunteer or paid respite care services which provide short term, temporary care for an impaired older person to relieve the family members who provide daily care to their relative.*

10. Adult Day Care Services
Adult day care services may be available in

*See page 37 for the telephone number of the agency to help you.

your community. This type of service provides social and some rehabilitative activities for the frail older person during the day in a community facility.*

11. Counseling

Communities often offer guidance and assistance for older persons and families in coping with physical impairments and such problems as substance abuse, financial crisis, bereavement and elder abuse.*

12. Support Groups

Groups have been formed in many communities that provide information and emotional support to older persons and/or their caregivers. These groups frequently focus on special needs such as Alzheimer's Disease, terminally ill persons, bereavement and other serious life situations.*

13. Reassurance

To reassure older persons living alone, many communities provide daily telephone contact, friendly visiting, the U.S. Postal Service's "Carrier Alert" program and emergency assistance programs.*

14. Social/Recreational Activities

Many communities support group activities for social, physical, religious, and recreational

*See page 37 for the telephone number of the agency to help you.

purposes. Senior Centers offer a good opportunity for recreation and social involvement with others. There are a number of other groups that focus on special interests such as arts and crafts, education, travel, and other interests.*

*See page 37 for the telephone number of the agency to help you.

LEGAL SERVICES

Many communities offer legal services. For those elderly who are unable to appropriately manage their own affairs, legal and/or protective services may be needed. Such services are designed to safeguard the rights and interests of older persons, to protect them from harm, to protect the property of older persons and to provide advice and counsel to older persons and their families in dealing with financial and business concerns. Many communities have a Bar Association which makes referrals to practicing attorneys. Some legal issues that older persons and their families may be interested in could include:

1. Power of Attorney

This is a legal device which permits one individual known as the "principal" to give to another person called the "attorney-in-fact" the authority to act on his or her behalf. The attorney-in-fact is authorized to handle banking and real estate, incur expenses, pay bills and handle a wide variety of legal affairs for a specified period of time. The Power of Attorney can continue indefinitely during the lifetime of the principal so long as that person is competent and capable of granting power of attorney. If the principal becomes comatose or mentally incompetent, the Power of Attorney automatically expires just as it would if the principal dies. Therefore, this Power of Attorney may expire just when it is most needed.*

*See page 37 for the telephone number of the agency to help you.

2. Durable Power of Attorney

Because Power of Attorney is limited by competency of the principal, some States have authorized a special legal device for the principal to express intent concerning the durability of the Power of Attorney to survive disability or incompetency. This legal device is an important alternative to guardianship, conservatorship, or trusteeship. The laws vary from State to State and since this puts a considerable amount of power in the hands of the attorney-in-fact, it should be drawn up by an attorney licensed to practice in the State of the client. This device is to compensate for the period of time when an individual becomes incompetent to manage their own affairs appropriately.*

3. Guardianship

Guardianship or conservatorship is a legal mechanism by which the court declares a person incompetent and appoints a guardian. The court transfers the responsibility for managing financial affairs, living arrangements, and medical care decisions to the guardian.*

4. Wills

A well prepared will is an effective tool which provides explicit instructions for the distribu-

*See page 37 for the telephone number of the agency to help you.

tion of property and if appropriate, how that property is to be used after a person dies. Information about burial or cremation can also be included. A will designates an individual or individuals to serve as the executor(s) responsible for carrying out the instructions of the will. Generally, a will makes it easier to settle affairs more quickly and with less legal expense.

5. The "Right to Die": Living Wills

Public attention is increasingly focused on "right to die" issues as advancing medical technology makes it possible to sustain, almost indefinitely, some vestige of life in dying patients. The term "right to die" refers to individual decision making regarding the prolongation of life through the use of extreme measures. The instrument or legal provision which enables others to carry out a person's wishes regarding the non-use of extreme life sustaining measures is called a Living Will.

Many States have enacted statutes which enable persons to make a Living Will. A Living Will is a signed, dated and witnessed document which allows a person to state wishes in advance regarding the use of life sustaining procedures during a terminal illness. This document indicates the appointment of someone else to direct care if the patient is unable to do so. It should be signed and dated by two witnesses who are not blood relatives or beneficiaries of property. A Living Will

should be discussed with the doctor and a signed copy should be added to the individual's medical file. A copy should be given to the person who will make decisions in the event that the older person is unable to do so. It should be reviewed yearly to make changes as needed.*

6. Other Issues

A. Issues concerning property, estates and trusts are governed by State laws and in some cases, local ordinances. If finances do not permit hiring a private attorney, there are programs that provide both legal advice and legal representation in court to elderly and low income persons. For information, contact the local Bar Association or Area Agency on Aging.*

B. Sometimes, tenant/landlord issues arise regarding leases, services, rental rights and obligations. To get advice, contact your landlord tenant advisory council, a lawyer, or the local Area Agency on Aging.*

C. Questions about family responsibility for financial support for health care, medical and/or long term care frequently arise. Families may need to seek legal advice about their obligations.*

D. It is important for the consumer to make informed choices when planning funeral ar-

*See page 37 for the telephone number of the agency to help you.

rangements. Collection of information on the cost of desired arrangements and preplanning can help families avoid hasty, and often times expensive, decisions. Consumers have a right to choose only those funeral and cemetery arrangements they desire. A new funeral rule specifies that funeral providers must disclose the cost of all goods and services, and upon the request of the consumer, must provide a written price list.

Families may choose to have traditional funeral services, direct interment, cremation and memorial services. Body or organ donation may be another consideration.

Availability of death benefits should be ascertained. In some cases, these benefits could have a direct bearing on planning funeral arrangements. Death benefits may be derived from Social Security, the Veterans Administration, life and casualty insurance and other sources depending upon the circumstances at the time of death.

Many older persons have specific wishes about how the funeral is to be conducted and burial arrangements. Those wishes should be put in writing and left where they can easily be found by a responsible family member.*

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SHELTER

1. Congregate and Senior Housing Apartments

Congregate and group living arrangements are available for rental to older persons in many communities. Some facilities are privately financed and others are publicly assisted. In those communities which have congregate living facilities for low income older persons, application for a subsidized rental unit is made through the local Housing Authority.*

2. Accessory Apartments

An accessory apartment is an independent living unit with its own outside entrance, kitchen, and bath. Accessory apartments may be especially desirable for younger families who want their older relative(s) near, or for older residents of large houses with space that could be converted into an accessory apartment.*

3. Retirement and Life Care Communities

There are a variety of retirement and life care communities available in different parts of the country. Many retirement communities offer single family dwellings, rental apartments, condominiums and cooperatives which are sold or rented in the usual manner. In many of these communities, only the usual com-

*See page 37 for the telephone number of the agency to help you.

munity services such as police and fire protection, are available to residents. Other communities offer transportation, home delivered meals, and some in home services. It is important to inquire about what services are available and whether there are additional fees for these services.

In some parts of the country, living arrangements referred to as "life care communities" are available. In these communities, the resident, upon application, makes a one time payment and agrees to pay a monthly fee for services provided. The initial payment may range from $15,000 to $175,000 or more, depending upon the location and amenities offered. Monthly fees may range from $150 to over $2,000 or more for maintenance, chore services, housekeeping, meal and other personal care services. Many of these facilities have a "graduated care" arrangement which permits the resident to move from their own apartment into a nursing home unit, which includes skilled nursing home care, if needed. Frequently, these units will arrange for basic medical services. State and local regulations and requirements governing the operation and financing of these facilities vary considerably. Some States have no regulations or requirements regarding such facilities while other States prohibit the development of such facilities.

Facilities which are well designed and

carefully administered offer comfortable and independent living to many older persons. In all instances, if a family is considering this as a desirable housing alternative, an on-site visit to the facility and careful checking into the financial solvency of the organization is a *must*. Before entering into any contractual arrangements with such a facility, an attorney should be consulted.*

4. Shared Housing and Home Matching Programs

Shared housing is a living arrangement in which two or more unrelated individuals share the common areas of a house or apartment, while maintaining their own private space such as a bedroom. In home matching programs, potential home or apartment sharers are introduced to home or apartment seekers. Shared housing arrangements have three primary benefits. Financial benefits are derived from pooling resources to pay the rent, utilities, and other expenses associated with maintaining a home. A second benefit results from sharing the responsibilities for homemaking chores with others. Social interaction with other residents of the shared house is a third important benefit. Arrangements for shared housing can be made by individuals or by a public or private agency.*

*See page 37 for the telephone number of the agency to help you.

5. Echo Housing and Mobile Homes

Echo housing or "granny flats" are usually small living units in the back or side yards of a single family home. A mobile home can offer many of the same advantages of proximity to the family that echo housing does. However, zoning restrictions may prohibit such an arrangement in urban areas.*

*See page 37 for the telephone number of the agency to help you.

State Agencies on Aging

In which state is the community you are concerned with located? Find the state below and call the agency listed. It will provide you with the telephone number of the **Area Agency on Aging** for that community. Call that agency to get the help you need!

State Agency:	Telephone Number:
Alabama Commission on Aging	(205) 261-5743
Older Alaskans Commission	(907) 465-3250
American Samoa Territorial Administration on Aging	(684) 633-1252
Arizona Office on Aging and Adult Administration	(602) 255-4446
Arkansas Department of Human Services	(501) 371-2441
California Department of Aging	(916) 322-5290
Colorado Aging & Adult Services Division	(303) 866-5122
Connecticut Department on Aging	(203) 566-3268

State Agencies on Aging

Delaware Division on Aging	(302) 421-6791
District of Columbia Office of Aging	(202) 724-5622
Florida Aging and Adult Services	(904) 488-8922
Georgia Office of Aging	(404) 894-5333
Guam Public Health and Social Services	(671) 734-2942
Hawaii Executive Office on Aging	(808) 548-2593
Idaho Office on Aging	(208) 334-3833
Illinois Department on Aging	(217) 785-3356
Indiana Department on Aging and Community Services	(317) 232-7006
Iowa Commission on Aging	(515) 281-5187
Kansas Department on Aging	(913) 296-4986
Kentucky Division for Aging Services	(502) 564-6930
Louisiana Governor's Office of Elderly Affairs	(504) 925-1700

State Agencies on Aging

Maine Bureau of Elderly	(207) 289-2561
Maryland Office on Aging	(301) 225-1102
Massachusetts Department of Elder Affairs	(617) 727-7751
Michigan Office of Services to the Aging	(517) 373-8230
Minnesota Board on Aging	(612) 296-2770
Mississippi Council on Aging	(601) 949-2013
Missouri Division of Aging	(314) 751-3082
Montana Community Services Division	(406) 444-3865
Nebraska Department on Aging	(402) 471-2307
Nevada Division for Aging Services	(702) 885-4210
New Hampshire State Council on Aging	(603) 271-2751
New Jersey Division on Aging	(609) 292-4833
New Mexico State Agency on Aging	(505) 827-7640

State Agencies on Aging

New York State Office for the Aging	(518) 474-4425
North Carolina Division of Aging	(919) 733-3983
North Dakota Aging Services	(701) 224-2577
Northern Mariana Islands Department of Community and Cultural Affairs	(670) 234-6011
Ohio Commission on Aging	(614) 466-5500
Oklahoma Services for the Aging	(405) 521-2281
Oregon Senior Services Division	(503) 378-4728
Pennsylvania Department of Aging	(717) 783-1550
Puerto Rico Gericultura Commission	(809) 724-1059
Rhode Island Department of Elderly Affairs	(401) 277-2858
South Carolina Commission on Aging	(803) 758-2576
South Dakota Office of	(605) 773-3656

State Agencies on Aging

Adult Services and Aging	
Tennessee Commission on Aging	(615) 741-2056
Texas Department on Aging	(512) 444-6890
Trust Territory of the Pacific Islands Office of Elderly Affairs	(670) 322-9328
Utah Division of Aging and Adult Services	(801) 533-6422
Vermont Office on Aging	(802) 241-2400
Virgin Islands Commission on Aging	(809) 774-5884
Virginia Department for the Aging	(804) 225-2271
Washington Bureau of Aging and Adult Services	(206) 753-2502
West Virginia Commission on Aging	(304) 348-3317
Wisconsin Office on Aging	(608) 266-2536
Wyoming Commission on Aging	(307) 777-6111

ATTACHMENT B

The National Institute on Adult Daycare

The National Institute on Adult Daycare (NIAD) was established within the National Council on the Aging in 1979 to provide a focal point for adult day care at the national level. It was initiated through the efforts, and in direct response to the expressed need and demand, of day care practitioners from across the country. The institute was organized to promote day care as a viable option of a community-based program of services and activities for disabled older persons within the larger continuum of long-term care.

> *Adult day care is a community-based group program designed to meet the needs of functionally impaired adults through an individual plan of care. It is a structured, comprehensive program that provides a variety of health, social and related support services in a protective setting during any part of a day but less than 24-hour care.*
>
> *Individuals who participate in adult day care attend on a planned basis during specified hours. Adult day care assists its participants to remain in the community, enabling families and other caregivers to continue caring for an impaired member at home.*

PURPOSES OF THE INSTITUTE

- To provide a focal point for adult day care at the national level
- To promote the concept of adult day care by working with voluntary organizations and governmental agencies at all levels
- To stimulate further development and refinement of day care as a modality of service
- To provide opportunities for exchange of ideas and experiences in the delivery of adult day care
- To develop standards and guidelines for quality day care programs
- To provide training and technical assistance for service providers
- To organize efforts to achieve additional and more secure funding for the provision of adult day care
- To support the efforts and development of state associations on adult day care

CURRENT SERVICES AND ACTIVITIES

- Newsletter
- Regional and national conferences and workshops
- National standards
- Consultations
- Nationwide survey of adult day care centers
- Annotated bibliography
- Advocacy of public policy positions related to concerns of adult day care
- Survey of state adult day care regulations

NCOA THE NATIONAL COUNCIL ON THE AGING, INC.
Since 1950 working to improve the lives of older Americans
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Senator BRADLEY. Then, have you thought of any cost benefit analysis in terms of improved quality of life for the senior or increased productivity for the care giver if the care giver is allowed, because of adult day care, to go back to the job market?

Ms. SHILLINGLAW. We don't have anything other than the studies that we have cited. Again, intuitively, it is there, but it is very difficult to demonstrate and measure quality of life, for example.

Senator BRADLEY. Productivity increase is a little easier to determine.

Ms. SHILLINGLAW. A little easier, yes.

Senator BRADLEY. If somebody is back in the work force as opposed to being forced to stay at home.

What about any of the analyses of the number of people who are now in nursing homes who might actually be able to leave nursing homes if there were adult day care centers?

Ms. SHILLINGLAW. We would not have that kind of analysis, although, clearly, in States that have chosen to do adult day care under the home and community based waiver, to the extent that there are people in institutions in that State who have family who could bring them out and take advantage of those services, one would suppose that they do.

Senator BRADLEY. Thank you very much.

The CHAIRMAN. Thank you very much, Ms. Shillinglaw.

I will now recognize Senator Bradley for introducing the next witness.

Senator BRADLEY. Thank you very much, Mr. Chairman.

Our next witness is Ms. Carol Kurland from New Jersey. She is the head of the Office of Home Care Programs at the Department of Human Services. She has a wealth of experience in this area.

I think that New Jersey has really been on the forefront of adult day care services, and I think Mr. Chairman, she might actually address some of the questions that you posed to Ms. Shillinglaw and a number of others based upon the New Jersey experience.

We have worked together on a number of occasions, and I think that Ms. Kurland is really an outstanding public servant.

Ms. KURLAND. Thank you.

The CHAIRMAN. Thank you, Senator.

Welcome to the committee, Ms. Kurland. We are delighted to have your testimony.

Ms. KURLAND. Thank you, Senator Melcher, and thank you, Senator Bradley. I am very happy to be here.

STATEMENT OF CAROL H. KURLAND, ADMINISTRATOR, OFFICE OF HOME CARE PROGRAMS, NEW JERSEY DEPARTMENT OF HUMAN SERVICES

Ms. KURLAND. My name is Carol Kurland. I am the Administrator of the Office of Home Care Programs in the New Jersey Department of Human Services, Division of Medical Assistance and Health Services. That is a mouthful; that means New Jersey Medicaid.

My office is responsible for five 2,176 home and community based service waivers reimbursed by Medicaid which include adult day care and also for our statewide medical day care program. I have

been involved in adult day care for over 10 years and served on the National Council on Aging's National Institute on Adult Daycare, NIAD, and its committee which developed the adult day care standards in 1984.

Our department truly appreciates the opportunity to provide testimony in support of adult day health services and to share our experiences in implementing a Medicaid Title XIX funded program in New Jersey. I want to commend you, Senator Melcher, and the committee for scheduling these most important hearings.

New Jersey has been a proponent of adult day health care or medical day care, as it is known in our State, for many years. Medical day care was introduced as a statewide Medicaid service in May of 1977 as an important service in the long-term care continuum. We became the fifth State in the nation to use Medicaid dollars for adult day care.

Adult day care was developed after a study in our State which indicated that 35 percent of our intermediate care facility B patients were inappropriately placed and could be discharged if community based services were provided.

New Jersey's medical day care program was modeled after an informational memorandum issued by the then-United States Department of Health, Education, and Welfare in January of 1976. These Federal guidelines remain the only ones issued in this service area.

New Jersey decided to target our Medicaid eligible population to be served in medical day care as the chronically ill elderly or other disabled individuals over the age of 16 who were at the point of discharge from hospital or other acute care facility, or were residing in the community and in crisis, or were residents of nursing homes but inappropriately placed.

Initially, only long-term care facilities, nursing homes, were permitted by New Jersey Medicaid to become providers of medical day care services because of our uncertainty about how large this program would become. However, we realized that sufficient system controls existed to allow for a gradual expansion of these services.

In 1980, free-standing, independent clinic type programs were approved, and in 1982, hospital affiliated centers were accepted as medical day care providers.

A center must be approved under a certificate of need process and licensed by our State Department of Health prior to becoming a Medicaid provider.

Each person entering a medical day care center is certified by an attending physician as needing this care and an individualized plan of care prepared by the medical day care staff is performed initially and every 90 days to 6 months. The plan of care which has multi-disciplinary input is submitted to a Medicaid district office, and we have an office in 16 of our 21 counties in the State. It is submitted for review and authorization by a Medicaid medical evaluation team prior to the provision of services by the center.

This same team prior-authorizes home health and nursing home services. So, they are fully aware of the total care needs of an individual.

A Medicaid medical review team comprised of a physician, nurse, social worker, and pharmacist also visits each center several times during the year to monitor and evaluate the programs.

Against this background of a health care service developed to meet an identified need for community based care, medical day care in New Jersey has slowly grown over the past 11 years to a very visible needed option. Currently, there are 48 nonprofit and proprietary centers in the State, 23 nursing home based, 18 free-standing, and 7 affiliated with hospitals serving an average of 800 participants a month at a cost of $3.6 million of Federal and State monies in State fiscal year 1987.

By the way, our newest medical day care center is in Paterson, North Jersey serving persons with AIDS and ARC; I believe it is the first in the nation.

Since medical day care began as a nursing home based program, reimbursement has been related to the cost of nursing home care. Currently, Medicaid pays 55 percent of the intermediate care facility B, that is the ICFB rate—we have three levels of care in New Jersey—which averages $31 per day.

In New Jersey, Medicaid's annual net cost of an ICFB nursing home patient is $14,664.

Since medical day care services are provided on an average of three days a week, a participant who resides in the community with comparable needs to an ICFB patient costs Medicaid in New Jersey approximately $4,800 per year, a considerable savings to our program.

Data was recently compiled on 1,083 Medicaid clients in 38 centers. This is on a computer base in my office and will be a continuing informational source for our program.

Centers ranged in size from 6 to 109 participants with a median census of 33 and a mean daily attendance of 24.5 per center. Sixty percent of the individuals served were 65 or older, 18.6 were 55 to 64, and 21 percent were under 55. Ages actually ranged from 20 to 101.

Most participants were female, 75 percent. Racial characteristics were 44 percent black, 43 percent white, and 11 percent Hispanic, and over 88 percent were not married. Of these, 41 percent were widowed and 30 percent never married.

Most individuals live alone or with adult children or parents or in a boarding home situation. Over 33 percent had no primary caregiver, but for 20 percent, the adult child was the primary caregiver.

The most common significant diagnoses were cardiovascular disease and musculoskeletal disorders, but there were also significant numbers of clients with diabetes, eye disorders, mental illness, and retardation, miscellaneous neurosensory, nutritional, and metabolic disorders, and Alzheimers disease, diagnoses not dissimilar to those found in nursing home patients.

We see them as the same individuals, not as an additional group, as indicated by Ms. Shillinglaw.

Individuals attended the program because of their chronic physical health problems, recent deterioration of medical status, increased dependency, social isolation, and their care givers' need for relief.

The overwhelming majority, 93 percent, lived in the community and were considered at risk. Participants required health monitoring, therapeutic recreation and nutrition, social services, supervi-

sion or administration of medication. Few required physical, speech, or occupational therapy.

It is my understanding that you are also interested in hearing about some specific cases served in medical day care. Three actual cases illustrate the value of this service.

One is John, a 76-year-old widower who has lived alone since his wife's death four years ago. He was depressed, neglected himself, and used alcohol excessively. He was diagnosed as having epidermal cancer with involvement of lymph nodes under one arm.

After hospital treatment, he was admitted to a nursing home. He discharged himself from the nursing home, returned to his own home, and enrolled in medical day care for the necessary short-term health care monitoring.

He gained weight, emerged as a leader at the center, and developed a positive attitude. Although he is no longer enrolled at the center, he visits regularly and has become quite outgoing and social in his community.

The second situation is Mary, an 80-year-old diagnosed as hypertensive, demented, and hypothyroid, was admitted to a medical day care center. She was unresponsive with a flat affect, needed intensive prompting to walk and socialize.

The center provided medical and nutritional monitoring. The family was educated about her medical needs as well as her need for changes in the home environment.

Her blood pressure medication soon was no longer needed. She now eats independently, and incontinence is managed by frequent toileting.

She has become social, is known for a good sense of humor, and enjoys singing. The family states that medical day care was their last hope before nursing home placement and are delighted with the changes that have enabled her to remain home.

Finally, Catherine, an 83-year-old with a diagnosis of probable progressive dementia, Alzheimer type, had a history of visiting the local emergency room—a very expensive service to Medicaid, by the way—three or four times a week with numerous complaints. She also called her daughter constantly at her job.

The center provided counseling to the family in crisis. Staff taught the family expected behaviors and furnished resources for additional help.

As a result of her attendance at the center, the client's complaints diminished, and the emergency room visits became a thing of the past.

Families of participants are particularly laudatory about medical day care. They state that their loved ones are less depressed, have fewer outbursts of temper, are more cooperative at home, and, in general, there is improved family functioning. One son even stated that his mother's participation made it possible for him to cope with the stress of his own family's problems dealing with a bulemic son.

Our service providers also inform us that because of the serious shortage of home health aides in New Jersey, at times, the only health care option is medical day care. Although covered under both Medicare and Medicaid, home health services may be inaccessible and unavailable. If a person needs nursing and personal care

and is able to leave the isolation of the home, the added socialization activities available in a medical day care center can enhance the client's quality of life.

A comparison of the cost of medical day care in New Jersey which averages $31 a day versus home health care which could be $9 to $30 an hour in New Jersey demonstrates the cost effectiveness of this medical day care service.

In summary, we in New Jersey applaud the efforts of your committee to publicize the value of adult day health care. Our experience has shown that this service is an essential community based option which meets the needs of many New Jersey residents whose medical and social needs would go unserved or who would otherwise be forced to enter an institution.

Thank you.

[The prepared statement of Ms. Kurland follows:]

TESTIMONY OF CAROL H. KURLAND

ADMINISTRATOR, OFFICE OF HOME CARE PROGRAMS

NEW JERSEY DEPARTMENT OF HUMAN SERVICES

DIVISION OF MEDICAL ASSISTANCE AND HEALTH SERVICES

Mr. Chairman and Members of the Committee:

I am Carol H. Kurland, Administrator of the Office of Home Care Programs in the New Jersey Department of Human Services, Division of Medical Assistance and Health Services. My office is responsible for several home and community-based services programs reimbursed by Medicaid, among which is our statewide Medical Day Care Program. I have been involved in adult day care for over ten years and served on the National Council on Aging's National Institute of Adult Daycare and its committee which developed the adult day care standards in 1984.

Our Department appreciates the opportunity to provide testimony in support of adult day health services and to share our experiences in implementing a Title XIX-funded program in New Jersey. We want to commend the chairman and committee for scheduling these important hearings.

New Jersey has been a proponent of adult day health care or medical day care, as it is known in our state, for many years. Medical day care was introduced as a statewide Medicaid service in May 1977, as a health care alternative to total institutionalization. New Jersey became the fifth state in the nation to use Medicaid dollars for adult day care. In recent years medical day care has become a popular Medicaid service nationwide particularly within the Section 2176 Medicaid waivers. New Jersey has five waivers that provide medical day care as a vital service to our elderly and disabled within the continuum of long term care.

In 1977 New Jersey Medicaid was searching for a non-institutional health care option. The waiting lists for nursing homes were growing rapidly. A study commissioned by the state and carried out by the Urban Health Institute of New Jersey in September, 1977 revealed that 35% of those patients institutionalized at the Intermediate Care Facility B Level (ICFB) could have been discharged if appropriate services and settings were available.

New Jersey's Medical Day Care Program was modelled after an Informational Memorandum issued by the (then) U.S. Department of Health,

Education, and Welfare in January, 1976, relating to "Reimbursement under Title XIX, Social Security Act for Services to the Chronically Ill and Impaired in Alternative Settings." These Federal guidelines remain the only ones issued on this service area.

New Jersey decided to target the Medicaid eligible population to be served in medical day care as the chronically ill elderly or other disabled adults who:

- were at the point of discharge from hospital or other acute care facility.
- were residing in the community and "in crisis"
- were residents of nursing homes but inappropriately placed.

Initially, only long term care facilities were permitted by New Jersey Medicaid to become medical day care providers because of our uncertainty about how large the program would become. However, we realized that sufficient system controls existed to allow for a gradual expansion of these services. In 1980 freestanding "independent clinic" type programs were approved and in 1982 hospital-affiliated centers were accepted as medical day care providers.

To be approved as a New Jersey Medicaid provider of medical day care services, specific requirements must be met. They are:

1. Licensure by the State Department of Health including:
   a. Completion of the Certificate of Need process
   b. Adherence to Building Codes
   c. Meeting staff and documentation requirements

2. Approval by the Medicaid Division as to conformance with program standards of staff/services/documentation. A Center must be a separate identifiable program, with a distinct staff, operating five days a week/seven hours a day. Centers must provide eight basic services; medical, nursing, social services, transportation, personal care, dietary, social activities, and rehabilitative services.

   Staff must include a full-time Program Director, part-time Medical Director, full-time nurse, social worker, activities coordinator in a ratio of nine participants to one staff. Therapies must be available on the premises or under contract to the center.

The primary concern of both the State Department of Health and the State Medicaid office is the need for medical day care to be health-directed. This means that services provided and the persons served must conform to a medical model.

Each person entering a medical day care center is certified by an attending physician as needing this care. An individualized plan of care prepared by the medical day care staff requires a physician's certification through a physical examination performed initially, and every 90 days. The plan of care, which has multidisciplinary input, is submitted to a Medicaid District Office for review and authorization by a Medical Evaluation Team, prior to the provision of services by the Center.

A Medicaid Medical Review Team, comprised of a physician, nurse, social worker and pharmacist, also visits each center several times during the year to evaluate the program.

Against this background of a health care service, developed to meet an identified need for community-based care, medical day care in New Jersey has slowly grown over the past eleven years to a very visible needed option. Currently, there are 48 centers in the state; 23 nursing home-based, 18 freestanding and 7 affiliated with hospitals, serving an average of 800 participants a month, at the cost of $3.6 million in FY 1987. Centers may voluntarily target the elderly, Alzheimer's population, young adults with cerebral palsy, a population in need of rehabilitation. Centers are located in almost every county, in urban and rural areas, providing a uniform standardized program of services. They universally provide a therapeutic program of services geared to either improve or maintain an optional level of functioning.

A specialized program for AIDS and ARC patients, recently opened under the auspices of a drug treatment center, is the newest freestanding program. The services provided through this medical day care center will be covered as a regular Medicaid service and also under our specialized AIDS Home Care Waiver.

Since medical day care began as a nursing home based program, the reimbursement was related to the cost of nursing home care. Currently, Medicaid pays 55% of the Intermediate Care Facility B (ICFB) rate which averages $31 per diem. In New Jersey the annual net cost of an ICFB (nursing home) patient is $14,664. Since medical day care services are provided on an average of two-three days a week, a participant who resides in the community with comparable needs to an ICFB patient costs Medicaid approximately $4800 per year, a considerable saving to our program.

Data was recently compiled on 1083 Medicaid clients in 38 centers. Centers were found to range in size from 6 to 109 participants, with a median census of 33 and a mean daily attendance of 24.5 per center.

Sixty percent of the individuals served were 65 or older, 18.6 percent were 55-64, and 21.4 percent under 55. Ages actually ranged from 20-101. Most participants were female (75%). Racial characteristics were 44.4 percent black, 43.6 percent white, 11.3 percent Hispanic. Over 88 percent were not married. Of these, 41.3 percent were widowed, 31 percent never married.

Most individuals lived alone (34%), with adult children or parents (28%) or in a boarding home situation (14%). Over 33% had no primary caregiver. For 20 percent the adult child was the primary caregiver.

The most common significant diagnoses were cardiovascular disease and musculoskeletal disorders. There were also significant numbers of clients with diabetes, eye disorders, mental illness and retardation, miscellaneous neurosensory, nutritional and metabolic disorders, and Alzheimer's Disease, diagnoses not dissimilar to those found in nursing home patients.

Individuals attended the program because of their chronic physical health problems, social isolation, recent deterioration of medical status, increased dependency, and their caregivers' need for relief.

The overwhelming majority (93%) lived in the community and were considered "at risk." Participants required health monitoring, therapeutic recreation and nutrition, social services, supervision/administration of medication. Few required physical, speech or occupational therapy.

It is my understanding that you are interested in hearing about specific cases served in medical day care. Four actual cases illustrate the value of this service.

1. Florence, a 78-year old widow, currently living with a stepdaughter, neglected her own health while caring for her chronically ill husband. The staff at the center observed hematuria (blood in her urine). She was hospitalized and diagnosed as having cancer of the bladder. She has returned to the center and the staff coordinates her radiation therapy program and observes for side effects to the treatment. Without the medical day care participation, institutionalization may have been the only option.

2. John, a 76-year old widower, has lived alone since his wife's death four years ago. He was depressed, neglected himself and used alcohol excessively. He was diagnosed as having epidermal cancer with involvement of lymph nodes under one arm. After hospital treatment, he was admitted to a nursing home. He discharged himself from this long-term facility, returned to his home and enrolled in medical day care for the necessary short-term health care monitoring. He gained weight, emerged as a leader at the center, and developed a positive attitude. Although he is no longer enrolled at the center, he visits regularly and has become quite outgoing and social in his community.

3. Mary, an 80-year old female, diagnosed as hypertensive, demented and hypothyroid, was admitted to a medical day care center. She was unresponsive with a flat affect, needing intensive prompting to walk and socialize. The Center provided medical and nutritional monitoring. The family was educated about her medical needs as well as her need for changes in the home environment. Her blood pressure medication has been discontinued. She now eats independently and incontinence is managed by frequent toileting. She has become social, is known for a good sense of humor and enjoys singing. The family states that medical day care was their last hope before nursing home placement and are delighted with the changes which have enabled her to remain home.

4. Catherine, an 83-year old female with a diagnosis of probable progressive dementia, Alzheimer type, had a history of visiting the local emergency room three to four times a week with numerous complaints. She also called her daughter constantly at her job. The Center provided counseling to the family in crisis. Staff taught the family expected behaviors and furnished resources for additional help. As a result of her attendance at the Center, the client's complaints diminished and the emergency room visits became a thing of the past.

Families of participants are particularly laudatory about medical day care. They state that their loved ones are less depressed, have fewer outbursts of temper, are more cooperative at home and in general there is improved family functioning. One son stated his mother's participation made it possible for him to cope with the stress of his own family's problems, dealing with a bulemic son.

We in New Jersey strongly believe in the significance of adult day health care. We are also quite encouraged by the introduction of S1839 which would allow for its coverage under Medicare. This legislation truly represents a beginning national recognition of adult day health as a viable outpatient service for frail elderly and disabled patients. Although the utilization of Title XIX monies in our state has enabled many persons to use this community-based health care option, there are others whose income and resources exceed Medicaid's standards.

Centers are able to cite numerous individuals who need care, yet can not qualify for Medicaid, and are unable to meet the cost of medical day care privately. With the availability of this service under Medicare, they would be able to participate. Two examples are:

1. Emma is a 76-year old who suffered a stroke and needs extensive therapy. She lives alone, needs all of her $500/month income to maintain herself, has $6,000 in assets for "emergencies," exceeding Medicaid eligibility standards.
2. Earl is 85, has lived in the same house since 1940, and has severe heart problems. His income is $680/month and is needed for his maintenance. His son paid privately for medical day care for one month. However, the cost of raising four children, three in college at one time, made it impossible for the son to continue paying privately.

Service providers also inform us that because of the serious shortage of home health aides in New Jersey and in the nation, at times the only health care option is medical day care. Home health services may be inaccessible and unavailable. If a person needs nursing and personal care, and is able to leave the isolation of the home, the added socialization and activities available in a medical day care center could enhance the patient's quality of life. Additionally, the comparison of the cost of medical day care in New Jersey ($31 average a day) versus home care ($9 - $30 an hour) demonstrates the cost-effectiveness of this service.

In summary, we applaud the efforts of the Committee to publicize the value of adult day health. Our experiences have shown that this service is an essential community-based option which meets the needs of many New Jersey residents whose medical and social needs would go unserved or who would otherwise be forced to enter an institution.

The CHAIRMAN. Ms. Kurland, you are giving us some well rounded testimony here, and some which we sorely needed. One figure, though, sticks out and seems different.

You say medical day care in New Jersey—that is the term you use.

Ms. KURLAND. Yes, we have called it that for many years. It is very hard to change a name.

The CHAIRMAN. The average is $31 a day—and I think that is average—versus home care which is somewhere between $9 and $30 an hour for somebody to come in and help a little bit and bathe the patient, et cetera. I guess the $30 an hour would be a registered nurse.

Ms. KURLAND. More skilled, right.

The CHAIRMAN. Those figures seem to me to be about in the ball park of national averages, but you say that a nursing home patient in New Jersey costs $14,664. What is the average?

Ms. KURLAND. That is the annual net cost.

The CHAIRMAN. What is the average?

Ms. KURLAND. I really don't have those figures with me today, but we tried to compare this to the intermediate level which is the person who would most likely go to a day care center.

The CHAIRMAN. Which is a little bit different than just saying going to a nursing home. We have been using the figure of around $20,000.

Ms. KURLAND. Well, it could range up to $20,000 net. That is exclusive of the patient's income which is taken off the figure.

The CHAIRMAN. Yes, but for the $14,000, it is intermediate.

Ms. KURLAND. Right. I gave you the lowest figure, actually.

The CHAIRMAN. Now, out of that, how much does the State pay for Medicaid patients.

Ms. KURLAND. We pay 50 percent of costs.

The CHAIRMAN. Does the adult day care center, to the extent it is being used in Medicaid, save the Federal Government a little bit of money and the States a whole lot of money?

Ms. KURLAND. We think it does.

The CHAIRMAN. The States a whole lot of money? Is that right.

Ms. KURLAND. Well, I can say that it is not used to the extent that home health services are used. It represents a small part of our budget.

The CHAIRMAN. Let's just take one Medicaid patient. If the average were something like Ms. Shillinglaw stated—she didn't give New Jersey, I don't believe, but she cited three different States. If I read her testimony correctly or understood her testimony, the States get $8,000 or $9,000 on this waiver, or do they get half of the $8,000 or $9,000?

Ms. KURLAND. I see what you are saying. What I was talking to was our statewide program, not the waivers.

The CHAIRMAN. Not the waivers.

Ms. KURLAND. No. We have adult day care both within our Medicaid waivers and also we have a statewide service of medical day care which is paid for under the clinic option. We are allowed to do that as an optional service under Title XIX.

What I am talking to primarily is our statewide option. We have approximately 800 individuals a month in the regular Medicaid

program. In addition, we have others that are being served under our five community based waivers, and I haven't given you that data.

The CHAIRMAN. What would you receive on a per patient basis on the waivers?

Ms. KURLAND. We still get 50 percent.

The CHAIRMAN. So, both save the State and the Federal Government then.

Ms. KURLAND. In both areas. In fact, it is our elderly program in which we are providing medical day care services——

The CHAIRMAN. What are the dollar savings?

Ms. KURLAND. Under which program are you talking about?

The CHAIRMAN. Well, let's take the waivers first and then the others.

Ms. KURLAND. At present, under our elderly program, we are serving people at one-third of the cost of nursing home care.

The CHAIRMAN. One-third.

Ms. KURLAND. One-third of the cost under our waivers. The figures that HCFA gave you were much higher. Ours are showing a much lower figure, and one of the services provided within the waivers is medical day care.

I don't have it broken out as to what it costs within the waivers, but I can tell you we are saving the State and the Federal Government considerable monies.

And under the waivers, people have to be assessed as being eligible to meet nursing home criteria. In fact, we use the same teams in New Jersey, medical evaluation teams of physician, nurse, and social worker, who assess the patient going both into the nursing home and going into our waivers, and they use the same nursing home criteria to make that judgment.

So, we feel we are definitely targeting nursing home patients.

The CHAIRMAN. Well, that seems to contradict what we heard from Ms. Shillinglaw.

Ms. KURLAND. It is very hard to comment on that. They do get data from us. We submit annual HCFA 372 reports which are very difficult for us to do, and services are broken down in that report. It would seem to me that they should be able to extract some data to give you that information.

The CHAIRMAN. I would think so, too, and I was quite surprised that we didn't get more specific data on that. In this day and age where almost any Federal program that anybody participates in demands a great deal of paperwork, you would assume that paperwork would translate into facts and figures or at least projections of what would be reasonable facts and figures.

Those forms are what, 372?

Ms. KURLAND. HCFA 372's do break down the amount of money we spend on various service areas for the waivers. Also, our regular title XIV program has been in operation over 11 years. I don't want to ask for trouble, but HCFA has not been in to look at our medical day care program. They have never been in a medical day care center in New Jersey and really know little about the program.

The CHAIRMAN. Well, your experience is——

Ms. KURLAND. I am sure next week I will have a visit. [Laughter.]

But that is all right.

The CHAIRMAN. Well, I think it would be enlightening for HCFA. It seems like it is based on what we heard today.

However, your experience is that 93 percent were at risk, 93 percent of those that are in your medical care centers?

Ms. KURLAND. We are saying 93 percent are coming from the community and were considered at risk.

The CHAIRMAN. What does that mean, then?

Ms. KURLAND. That means they are meeting certain criteria as determined by our prior authorization medical evaluation teams that they need care or that they would need a higher level of care such as hospital or nursing home care.

The CHAIRMAN. Well, what is the other option, home care?

Ms. KURLAND. The other option is no care.

The CHAIRMAN. No care.

Ms. KURLAND. No care, home care, or institutional care.

The CHAIRMAN. So, when you say that you are looking at medical care centers, that type of care, and also home health care, those two, they are at risk for one or the other.

Ms. KURLAND. Right.

The CHAIRMAN. And your conclusion is that there is a great deal of saving if an individual can be channeled into a medical care center.

Ms. KURLAND. There certainly is. I mean, I am also a proponent of home care; don't misunderstand me.

The CHAIRMAN. No, we understand that.

Ms. KURLAND. But it is much cheaper in a medical day care center. There is no question about that.

And sometimes they happen together. We serve them together.

The CHAIRMAN. I do hope that HCFA does visit you right away from the standpoint of learning first-hand. You were here, I think, when we had the four-minute video, and I said seeing is believing.

Ms. KURLAND. I agree.

The CHAIRMAN. So, perhaps by visiting you, they could become better believers in how we could save some money as well as improving the quality of life for individuals.

I want to thank you very much, Ms. Kurland.

Senator Bradley.

Senator BRADLEY. Thank you very much, Mr. Chairman.

I thought you would find Ms. Kurland's testimony an interesting counterpoint.

I would just like to go over some of the facts that you have given to nail down some of the numbers so that the record will fully reflect the New Jersey experience.

Ms. KURLAND. All right.

Senator BRADLEY. Ms. Shillinglaw contended that adult day care was an additional service that was provided to individuals who would not be in a nursing home and, therefore, it is not a savings in that sense. You have said that in the New Jersey experience, which is over 11 years, that the health review teams say that 93 percent of the people who receive adult day care would or should

be receiving some form of care. If not adult day care, then they would be in a nursing home.

Is that correct?

Ms. KURLAND. No. Actually, what I am saying is that 100 percent are in need of the service, but 93 percent have been determined to be living at home and at risk rather than coming out of nursing homes. It is a little different.

All individuals entering medical day care are considered basically in need of care, but there are three different groups. One is in crisis and enters from the home, one is at risk of going into a nursing home or hospital, a third group is inappropriately placed in a nursing home and could potentially use care in a medical day care center. Maybe I confused you on that.

All people require care as determined by our teams. We prior authorize all of our services, and they all meet the criteria which says they are at risk.

Senator BRADLEY. And the 93 percent figure is what?

Ms. KURLAND. Are living in the community and are in crisis. The remainder have come out of nursing homes or hospitals or are at risk of placement.

Senator BRADLEY. What other comments do you have to the contentions that HCFA made this morning?

Ms. KURLAND. Well, I guess what disturbs me is they seem to treat medical day care only as a part of the total package of services under these waivers. First of all, they have never looked at it as an individual service, and I don't believe under Channeling they have ever looked at it as a single service. It is very important in its own right.

Secondly, the fact that in our waivers individuals must meet a nursing home level of care indicates that we are targeting individuals appropriately. We are not adding a group of people who would not be served otherwise.

Senator BRADLEY. So that under the waiver programs, you are definitely displacing individuals who would be in the nursing home, because that is the criterion for the waiver.

Ms. KURLAND. But I don't believe they have any data on the service itself within the waivers. The report they referred to has not been shown to us. We have never seen a final copy of that report, so I really don't feel they have adequately collected data on this service area or on any other services within the waivers.

Senator BRADLEY. And every year in the waiver, you submit a report that contains what information?

Ms. KURLAND. We submit a breakdown of costs of specific services annually. Additionally, at the end of three years, we have to basically reapply to continue these waivers, and our elderly program was renewed for five more years, so we are in our sixth year of service now.

We have three small model waiver programs where we serve very sick people. Two of those have been extended, and the newest is, of course, our AIDS program.

But we have to submit annual reports and they monitor us. Region II comes in and monitors us annually on all of our programs. So, they are very much aware of the services we provide.

They have never disapproved anything. They have always given us superlative ratings on all of our programs.

So, obviously, they are very supportive of these kinds of community services, a fact that she really did not attest to too satisfactorily.

Senator BRADLEY. And just once more the numbers. The nursing home patient annual net cost is $14,664?

Ms. KURLAND. Correct.

Senator BRADLEY. And the cost of meeting the needs of that individual if the individual resided in the community and had adult day care would be $4,800?

Ms. KURLAND. Yes, that is correct.

Senator BRADLEY. So that if you were looking at individuals and say is it more efficient to be in adult day care versus being in a nursing home, you save essentially $10,000 per person?

Ms. KURLAND. That is how it appears to me.

Senator BRADLEY. Then, the other figure that I would call attention to in your testimony is the cost of medical day care in New Jersey at $31 average per day, and that compares on the home care side at $9 to $30 per hour.

Ms. KURLAND. Correct.

Senator BRADLEY. So that among the range of services, adult medical day care is clearly the most cost efficient.

Ms. KURLAND. If a person is able to leave the home and get the services in a medical day care center, the personal care, nursing services required, it certainly is a very cost effective and efficient way to go.

Senator BRADLEY. In addition to the personal cases which I think were really excellent—I applaud you for putting them in—I think they make it real, as the first witnesses did, the other number that my eye caught in the testimony is that, 31 percent of those involved in medical day care never were married.

Ms. KURLAND. That is correct.

Senator BRADLEY. So that means probably——

Ms. KURLAND. No family.

Senator BRADLEY. That there is no one in the world with whom they have any kind of association or relation whatsoever with the exception of maybe the friends or neighbors that they have made over the years, right?

Ms. KURLAND. Yes.

Senator BRADLEY. You point out that over 88 percent of the people were not married at the time of the survey 41 percent of these were widowed and 31 percent never married. So, this really means that if they don't get either a combination of adult day care medical services and/or home care, they just can't make it.

Ms. KURLAND. That is true.

Senator BRADLEY. They are going to end up in a nursing home, and these are largely elderly women who are alone in an apartment or small house somewhere and increasingly isolated by deteriorating health.

Ms. KURLAND. That is correct.

Senator BRADLEY. Well, Ms. Kurland, I think that your testimony and the statistics that you provide not only in terms of cost effectiveness for adult day care but also in terms of human need are

really compelling, and I think you have helped Senator Melcher and I build a case here for what we are trying to do.

Thank you very much.

Ms. KURLAND. Thank you very much.

The CHAIRMAN. Thank you, Ms. Kurland.

We will keep this hearing record open for 10 days for any additional comments or testimony that is written that anyone would care to make.

With that, the committee is adjourned.

[Whereupon, at 12:14 p.m., the committee adjourned, to reconvene subject to the call of the Chair.]

APPENDIX

Item 1

American Pharmaceutical Association
APhA
2215 Constitution Avenue, NW
Washington, DC 20037
(202) 628-4410 FAX (202) 783-2351
The National Professional Society of Pharmacists

John F. Schlegel, PharmD
President and CEO

Charles R. Green
Chairman of the Board

April 29, 1988

The Honorable John Melcher
Chairman, Senate Special Committee on Aging
Room G41
Dirksen Senate Office Building
Washington, DC 20510-6400

Dear Chairman Melcher:

The American Pharmaceutical Association (APhA) is pleased to submit comments for your April 18, 1988 hearing record on "Adult Day Health Care: A Vital Component of Long Term Care." APhA is the national professional society of pharmacists representing the third largest health profession, comprising more than 150,000 pharmacy practitioners, pharmaceutical scientists and pharmacy students.

APhA shares the sentiments you expressed in your opening statement at the April 18th hearing about the need to make adult day health care programs a high priority as an integral part of long term care. APhA commends you for your continued leadership in addressing the health care concerns of America's elderly and disabled. Adult day health care programs, and the professional, individualized and cost-effective care they offer, are not only vital to the health and well-being of the participants, but also to family caregivers and friends. Programs that will provide individuals with the health, personal, nutritional, therapeutic and other services that will allow them to live in communities and out of long term care institutions are necessary and we applaud your efforts to address this issue.

In the remainder of this letter, we will address why we believe that any legislation addressing the issue of long term care should explicitly recognize the need for pharmaceutical services. More specifically, APhA believes that if you proceed with S. 1839, the "Medicare Adult Day Health Care Amendments of 1987", it should include pharmaceutical services in its description of the medical and other health care services that should be provided in adult day health care centers.

The term "adult day health care" is defined in S. 1839 as "a program of medically supervised, health and health-related items and services furnished by an adult day health care center in an ambulatory group care setting...". These services are enumerated and include medical, psychological, nursing, social, nutritional and other related services. However, there is no mention of pharmaceutical services, which are provided by pharmacists.

Pharmacists play an important role in assuring high quality health care in all health care settings. While we understand that in adult day health care centers participants would bring their prescribed medications with them and thus the center would not generally be required to dispense medications, pharmacists perform numerous non-distributive professional functions that are valuable and necessary in the adult day health care setting.

Pharmacists provide in-service educational programs to the center staff on the proper storage and administration of medications. Pharmacists work with the center staff to maintain an accurate patient medication profile. This profile record allows the pharmacist to periodically review the participant's medication regimen, monitoring for drug interactions, duplications of therapy, and over or under-utilization of the prescribed medications. The consultation of the pharmacist also can be very effective in preventing adverse drug reactions.

Pharmacists also can counsel the participants in the center to help them understand the purpose and proper use of their medications and health care equipment, such as ostomy supplies, braces, and respiratory therapy devices. Such counseling assures not only that patients receive optimal benefits from their medications and health care equipment, but that they do not suffer from serious problems that could result from the inappropriate use of medications and equipment.

Some adult day health care centers are affiliated with long term care facilities and thus are required to meet the government-regulated standards for pharmaceutical services. APhA believes that the government's recognition of the need for pharmaceutical services in long term care facilities, such as nursing homes, should extend to all adult day health care centers. We therefore believe that all elderly and disabled participants in adult day health care centers need and deserve to have the professional services provided by pharmacists.

For the reasons we have set forth in this letter, APhA respectfully urges that you explicitly include pharmaceutical services in any legislation addressing long term care, including adult day health care centers.

Thank you for the opportunity to provide comments on this issue. We stand ready to assist you and your staff with further detailed information about the services that pharmacists can provide in adult day health care centers.

Sincerely,

John F. Schlegel, Pharm.D.
President

JFS/kac

Item 2

Statement of the Hon. Leon E. Panetta on Adult Day Care
Senate Special Committee on Aging
Senator John Melcher, Chairman
April 18, 1988

Mr. Chairman, I am delighted that you are today convening this hearing on the important subject of adult day care. As you know, I am the sponsor of a measure in the House, H.R. 550, that is a companion bill to S. 1839 that you have introduced in the Senate. The "Medicare Adult Day Care Amendments" are intended to help more of our nation's senior citizens and chronically ill stay in their own communities rather than being unnecessarily placed in nursing homes and other institutions away from their own homes and communities. I am very pleased that you have introduced the Medicare Adult Day Care Amendments in the Senate, and am very thankful for the opportunity to present testimony on adult day care as part of this hearing.

The need which this legislation attempts to address is part of a persistent yet neglected national problem that will not just disappear over time: the lack of a comprehensive national long-term health care policy. By now, the parameters of this problem have become familiar to most policymakers. The aging of the population over the next few decades -- due to both demographics and longer life expectancies -- will impose increasingly greater strains on an already overburdened system. The present structure of health care delivery and financing does not make effective use of total health care dollars. Entire segments of the population receive second-rate services. The United States is the only major industrialized nation in the world without a national health care policy. I think it is especially important in the context of this hearing that senior citizens today spend the same percentage of their personal incomes on health care as they did before the existence of Medicare.

Moreover, Medicare provides coverage mostly for acute care situations and largely frowns upon preventive health care services. Those requiring long term custodial care must either be wealthy enough to pay the exorbitant costs of such care out of pocket, or destitute enough to meet Medicaid eligibility requirements. The middle-income segment of the population follows the all-too-familiar "spend down" path, whereby they must deplete their lifelong savings before becoming eligible for any public assistance. While pending Medicare

catastrophic legislation would create some provision for the elderly to hold on to their resources, their savings are usually sufficient to cover only a short period of care; thereafter they become the responsibility of the state, under whose jurisdiction they remain indefinitely. Those critics who abhor the thought of Medicare coverage for preventive care because of "the expense" should play the scenario out a little bit further: today's Medicare patient unable to afford the relatively inexpensive costs of preventive or custodial community care is tomorrow's broke nursing home patient financially dependent on Medicaid. The "spend-down" requirement deprives many people of savings they have worked very hard over their lives to earn and build up. We should not shy away from shifting Medicare's focus to encompass preventive care because in the long run we will realize savings.

I believe it is high time that we begin to look at alternative means of caring for our nation's ill and elderly. We need to broaden our perspective on the health care issue. Over the past few years we have enacted significant reforms in the Medicare program which have resulted in more efficient delivery of currently covered services. These changes have been encouraging. Now, we should be exploring ways of redesigning our health care system to meet the "big picture" human and fiscal needs of years ahead.

An oft-discussed and much lauded approach is to maximize the amount of time the individual spends in a community setting, either with their families or on their own. Aside from the obvious human benefits of avoiding institutionalization, such a strategy makes fiscal sense as well. Measures designed to maximize a senior's independence and self-sufficiency should not be viewed as unnecessary luxuries but as sound investments.

Given the proper array of support services, countless senior citizens would be able to remain in the community for an extended period of time, reducing their dependence on publicly financed institutional care. The time has come to start putting into place the various components of a comprehensive system of long term care alternatives. Already communities across the nation are responding to the need as families and specialists are working together to implement creative solutions to the problem of caring for the aged. Adult day care is a particularly encouraging alternative that has attracted widespread attention.

Adult day care, as you know, is a community-based group program designed to meet the needs of functionally impaired adults through individually tailored plans of care. It is a structured, comprehensive program that provides a variety of health, social and related support services in a group setting on a less than 24-hour care basis. A multidisciplinary group of professionals -- including a physician, a registered nurse, a physical, occupational and/or speech therapist, and, if needed, a dietician -- work together to deliver the optimal configuration of services to meet the individual's needs.

Adult day care offers a number of unique benefits. It is cost-effective as compared to both institutionalization and home health care. The centers provide respite for primary care givers, reduce the incidence of acute illness through ongoing monitoring of health symptoms and preventive health care, and have been successful in avoiding or delaying institutionalization. In addition, clients, many of whom live alone, receive the vital psychological benefits of mental and social stimulation not available to them when confined to the home.

A 1982 evaluation of adult day care centers in California found that 87% of seniors who participated in the programs maintained or improved their level of functioning. This statistic is especially significant given the fact that 63% of the participants were eligible for institutionalization according to Medicaid Field Office Criteria. Clearly, it is possible to avoid both the costs and the trauma of institutionalization provided that the proper community-based services are available to those in need.

Adult day care centers are cost-effective means of delivering those services. Because the care is provided in a group setting, day care centers can capitalize on the efficiency of providing care to more than one individual without having to act as a residential facility as well. Participants' needs are evaluated, a comprehensive care package is developed, and the necessary services are provided in a focused, efficient and humane manner.

Adult day care has grown quickly at the grassroots level over the last decade from approximately 300 programs in 1977 to over 1400 today. Despite the success of these programs, funding is difficult to come by. Some states have taken advantage of a Medicaid waiver program to provide coverage for certain low-income participants, but the Medicare-eligible population must pay out-of-pocket for these services. The result is that only the very poor or very rich can take advantage of this cost-effective alternative form of health care.

Clearly, the need exists for some kind of adult day care coverage through the Medicare program. Accordingly, last year I first introduced the Medicare Adult Day Care Amendments. This legislation, reintroduced in the 100th Congress as H.R. 550, would allow certain Part B beneficiaries to participate in adult day care programs through their supplementary Medicare insurance plans. In order to be covered for this new benefit, it must be certified that participants would otherwise require a level of care furnished in a hospital, skilled nursing facility, or intermediate care facility if the adult day care services were not provided. In addition, no more than 100 days per calendar year would be covered, and utilization would be subject to a $5 per day copayment.

This bill, which had 21 cosponsors in the 99th Congress, currently has 85 in this Congress. In addition, Medicare Catastrophic Legislation currently under consideration by the House and Senate includes a provision for a study on adult day care to be done by the Department of Health and Human Services. Specifically, the bill requires that HHS conduct a survey of adult day care services currently being provided throughout the United States. Based on the survey results, it then requires HHS, within one year, to report to Congress with recommendations for appropriate standards for the coverage of adult day care services under Medicare.

Adult day care is a humane, cost-effective alternative form of health care of the sort that we as policymakers should be encouraging. Amid current talk of revising Medicare so that it can better meet the long-term health care needs of our nation's seniors, this hearing is an important occasion for providing information on a cost-effective, humane alternative to nursing home placement. We owe the American public the wisest and most efficient allocation of their hard-earned tax dollars; we owe elderly Americans the respect to allow them to live out their later years in the least restrictive, most dignified environment available. Adult day care can and should be an important component of our overall longterm care system, and the federal government should play a role in enabling the elderly to make full use of this and other community-based forms of care.

Item 3

AN OVERVIEW OF RESPITE CARE AND ADULT DAY CARE IN THE UNITED STATES

Prepared by Marcie Parker,
Senior Research Associate, InterStudy
for
the Senate Special Committee on Aging

June 14, 1988

"Caregivers" are people who are providing care to those who are impaired in some way (physically, mentally, emotionally) and who need help with aspects of their daily living. "Informal caregivers" are those who are unpaid and provide this care on a voluntary basis. Informal caregivers may be family members, friends, neighbors, or church volunteers. They provide care to people of any age (i.e., children, adults, older persons) for as little as one hour a month to as much as 24 hours a day, seven days a week. The kinds of care that may be needed and provided by caregivers can include: personal care (e.g., bathing, feeding, toileting); health-related services (e.g., giving medications, rehabilitation, IV therapies); transportation/escort services (e.g., driving someone to the doctor and shopping); household/homemaking services (e.g., housecleaning, storm windows, snow removal); meal preparation; shopping and errands; linkage tasks (e.g., finding and arranging for services); and financial and legal management. Depending upon one's functional impairment, caregivers may provide as much care within the home as is provided in a nursing home with a full-time, round-the-clock paid staff.

It is estimated that approximately 80% of the care that is given to the functionally impaired in the United States is provided by family members and other informal caregivers. According to Evelyn Greb, division chief of long-term care with the San Diego Area Agency on Aging, it should be recognized just how much caregivers give to society. "Besides owing them a tremendous debt on humanitarian grounds, we have a tremendous self-interest in seeing that family caregivers are not left to cope alone. Without their willingness to nurse sick spouses and parents, taxpayers would have to fund the institutionalization of many more people. If we take the Older Women's League estimated figure of 76% as the proportion of care provided by family rather than paid services, you can come up with a $2 billion bill in San Diego County alone."[1] It is further estimated that for every one person receiving care in a nursing home, there are two in the community receiving the same level and amount of care.

"Respite care" means that someone is substituting on a temporary basis for a caregiver to give him or her relief -- a break from providing care. Respite care takes many forms: the person receiving the care may go into a nursing

home for a weekend or a couple of weeks, or he/she may attend an adult day care center or other community agency 1-5 days a week, or someone may go into the home for an hour/day/weekend/month to give the caregiver a respite or break.

Caregivers need to know that they are not alone! For example, the number and proportion of older persons continues to increase and will do so until 2050 AD. The 85+ age group is the fastest growing in the United States. In addition, 56% of all American women (the most likely caregivers) are in the workforce. 25-33% of workers in the workforce have some caregiving responsibilities for older relatives. And 40% of the workforce are working parents -- who may therefore be "sandwiched" between caregiving responsibilities for both young children as well as for frail elderly dependents.[2]

In a study of family caregivers and their support by the Benjamin Rose Institute, it was found that, "Even though most caregivers reported only mild or moderate amounts of stress, their lives were still affected by caregiving responsibilities:

- Four out of five caregivers indicated that some aspect of helping was difficult, tiring, or emotionally upsetting.
- Six out of ten said they had no clear idea about what was best to do in the caregiving situation.
- More than half said the person they cared for made too many demands on them."[3]

Respite care and adult day care are extremely important for caregivers for many reasons.

- A major, new study by the University of California has shown that there is a significant shift in the acuity of care throughout the whole health care system (i.e., hospitals are now high-tech trauma centers -- many patients who used to be cared for in hospitals are now being treated in sub-acute transitional care units or nursing homes -- those who used to be in nursing homes are now in community services and/or at home -- and those who used to be in adult day care are now in senior centers and at home). This shift in acuity has resulted in a greater burden for a longer period of time on families. Patients are sicker and older, and require more services.[4] In addition, home health care services are much more complex and high-tech as well, sometimes requiring that families be trained to do complex procedures such as IV chemotherapy and dialysis at home.

- Despite the fact that respite care and adult day care are very important services which permit families to continue giving care at home and despite

the fact that surveys show that respite care heads the list of services requested by caregivers, about "... 80% of all respite services nationwide are underused."[5] These services are underutilized for a number of reasons:

(a) There is a need for community education and publicity so that families know what services exist and where to locate them.

(b) Family dynamics may be very complex -- caregivers often feel guilty about asking for help, be reluctant to give up control, and may "need to be needed".

Professionals who do formal assessments of family needs often recommend more services to families than the families ever make use of. Therefore, fears that families will "come out of the woodwork" to use services seem unfounded, particularly with respite care and adult day care.

- To further assess the potential "substitution effect," information concerning the nature of caregivers is required. The majority of these data are from the Informal Caregivers Survey (ICS), a component of the 1982 Long Term Care Survey (LTCS) conducted by the Department of Health and Human Services to study disabled elderly persons living in the community. The following are some of the findings from that study (U.S. House of Representatives, 1987; Dunn and Gallaway, 1986):

  (a) Approximately 2.2 million caregivers aged 14 or older provided unpaid assistance to 1.2 million noninstitutionalized elderly disabled persons. The average age of the caregiver population was 57.3 years. 71.5% were female, 28.9% were wives, and 13% were husbands.

  (b) While fewer than 10% of the caregivers reportedly quit their jobs to care for a disabled relative or friend, a sizable proportion (69%) of all caregivers had to rearrange their schedules, reduce their work hours, and/or take time off without pay to fulfill caregiver obligations.

  (c) Family caregivers provide between 80-90% of the medically related care, personal care, household maintenance, transportation, and shopping needed by older persons.

  (d) Approximately 80% of noninstitutionalized disabled elderly persons rely solely on informal care.

  (e) 75% of all noninstitutionalized care (home health care, homemaker services, adult day care) is privately financed by the elderly and/or their relatives. Among the 1.1 million impaired older persons who received home care in 1982, 41% paid for these services out-of-pocket. The average payment was $164/month.

  (f) Informal caregivers, and family members in particular, are motivated

largely by love and affection toward the older person, a sense of gratitude and a desire to reciprocate help that was provided by the elderly person at an earlier stage, as well as by allegiance to a more generalized societal norm of spousal or filial responsibility.

(g) While there are many benefits of caregiving, there also are many stressors. These include:

- personal limitations from restrictions on one's social and professional life;
- competing demands from family members and work obligations;
- the care recipient's emotional and physical demands arising from erratic behavior, confusion and forgetfulness, and incontinence;
- emotional strain giving rise to depression, anxiety, lowered morale, and emotional exhaustion; and
- financial and family strain.

Similar qualitative results were found in studies in New York and Minnesota (Thorsheim, 1987).

In spite of these stressors, supporters of adult day care argue that studies have not substantiated nor supported fears about either the "woodwork" or "substitution" effect. In addition, they claim that the concerns are pernicious if their effect is to slow the development of adult day care utilization.

Without respite care, burnout of the caregivers may occur. Burnout occurs when the caregiver is overwhelmed and overloaded with caregiving and emotional and physical fatigue results. The caregiver is giving out more than he/she is receiving in return. In addition, research has shown that the health of caregivers may be seriously compromised by caregiving. Caregivers may suffer knee and back problems (from lifting, transfering, and wheeling the patient), depression and severe sleep disturbance (especially if caring for someone with Alzheimer's disease who "wanders" at night), and financial and emotional stress. Indeed, some caregivers have become drug and alcohol abusers to seek relief from their enormous burden.[6]

In a recent report on information released by the National Institute on Aging and reported in Health Policy Week, the impact of Alzheimer's disease was spelled out. "Professional care for victims of Alzheimer's disease and related dementias cost more than $13 billion in 1985, excluding medical expenses. In addition, NIA researchers estimate that the disease caused a $43 billion productivity loss for that year."[7] Due to the nature of the disease, caring for a victim of Alzheimer's disease is one of the most difficult kinds of care

that anyone -- health care professional or family member -- can provide. The problem of caregiving is beginning to have an enormous impact on young to middle-aged adults who are trying to care for children, hold down jobs, and care for frail, disabled children and elderly. A number of surveys of employees of corporations[8] have shown that at any given time, approximately 25-28% of employees are involved in caregiving for an older relative. Some employers are seeing an increase in absenteeism, repeated tardiness, inappropriate phone calls to and from work to check up on a relative at home, inappropriate sick days and vacation leaves, distraction and lack of concentration on the job, lack of motivation, and overall poor job performance by employees caring for an elderly relative. "One study of 69 companies in the greater New York area indicates that approximately half are aware of caregiver needs and many have identified employee problems in the workplace (e.g., lateness, absenteeism, etc.). Few have programs designed specifically for caregivers. However, larger companies and those with a predominantly female workforce have more policies and programs that can accommodate caregiver needs. Various strategies [are] currently being tried by companies to support caregivers."[9]

In fact, if the burden of care becomes too great, caregivers may quit work completely to care for someone. This means that the caregiver (usually, but not always, a woman) who no longer has income and withdraws from Social Security and pension plans, is at risk of becoming a poverty-stricken older person him/herself. Therefore, while society <u>may</u> save money in the <u>short run</u> (by having a frail older person cared for by a relative), in the <u>long run</u> these caregivers will become poor older persons in need of services themselves.

There is a lot of documentation to show that families are not "deserting" their elderly, but that providing care is becoming more difficult. This is because people are living much longer (4, 5, or even 6-generation families are no longer uncommon), they are sicker (with multiple long-term chronic problems), there are more of them, there are more women in the workforce rather than at home, and our society is quite mobile so families are often geographically separated. In addition, there is some anecdotal evidence that even after a patient enters a nursing home, families still provide a great deal of informal care (e.g., families visit their relatives in the nursing home to socialize and visit and feed relatives, take them home for visits and shopping, celebrate holidays and birthdays, and take home laundry to do).

Caregivers can be assisted in many ways to help them carry on with their caregiving. For one thing, they should not be praised for being "super

caregivers", but should instead be praised for accepting outside help, making decisions which take into account the family as a whole, and letting go of control. We must recognize that respite care is good for the whole family.[10]

Respite care -- to give everyone, including the patient, a break -- is "... a service that provides family caregivers with intervals of relief from the demands of their caregiving roles. Service providers, researchers, and caregivers themselves have long known that family members who take care of chronically ill, developmentally disabled, or physically handicapped relatives need periods of time off, both to protect their own physical and mental health and to allow them to maintain the quality of the care they are providing."[11] This report, by The Brookdale Foundation, outlined the factors which have contributed to the current interest in the development of respite programs:

1) Most Americans regard the care of their infirm aged relatives as a family responsibility. In fact, 80% of the care provided to chronically ill or mentally impaired older people living at home is provided by family members -- usually spouses or daughters.
2) The evidence suggests that families do better in the provision of this care if they have help from social service and health care systems and professionals.
3) The provision of in-home or community-based services has taken on an added attractiveness as a cost-containment strategy.
4) A final agent for change has been the formation, and increasing strength and visibility, of the Alzheimer's Disease and Related Disorders Association (ADRDA).

At this time, there are three general approaches to the delivery of respite services: providing a surrogate caregiver in the home of the cognitively impaired older person; placing the impaired person temporarily in a long-term care facility; and adult day programs. Some caregivers may make regular use of all these forms of respite care in order to continue to provide giving care for a longer period of time.[12]

In an East Bay Respite Care Survey, prepared for The Alameda County Respite Care Community by The Peabody Group, caregivers told us what kinds of respite care they want:

1) most caregivers surveyed prefer in-home care;
2) the most important factors in choosing respite services are specially trained and certified staff and cost;

3) most caregivers can spend no more than $50 for an 8-hour day of respite care but they can spend slightly more for a 24-hour day of care;
4) caregivers are most interested in day care in an organized setting and specialized care for Alzheimer's disease for out-of-home care; and
5) caregivers are most interested in home health aides, homemakers, and other friends and relatives for in-home respite care.[13]

One form of respite care is adult day care. A recent survey of adult day care centers by the NCOA nationwide reports that, "Seventeen years ago, there were only a dozen such centers. Now, an estimated 28,000 persons are served in adult day care facilities. Of an estimated 1,200 adult day care centers in the United States, over 70% responded to NCOA's companion survey. The average adult day care participant is female and 73 years old, receives an average monthly income of $478, and spends almost six hours daily at the center. Three-quarters of adult day care centers are private nonprofit organizations likely to share physical facilities with another program. Volunteer help flourishes. In 671 centers responding to this question, volunteers contribute 83,313 hours a month."[14]

Despite the importance of adult day care as one key way to provide respite care for caregivers, another NCOA study found that "... The climate [for the development of adult day care] is unfavorable or weak primarily in states where the economy is poor and funds are unavailable generally for programs benefitting elderly or disabled persons." The same study found that, "Questionnaire respondents felt that funding remains the major constraint in the growth of adult care programs."[15]

Adult day care centers provide a complex constellation of services designed to prevent premature institutionalization. These centers provide older persons with the option of remaining at home and continuing relationships with family and community rather than having to go into an institution prematurely. It is estimated that 25% of the people in nursing homes could use adult day health care rather than being institutionalized, thereby saving the federal government money by providing a less expensive alternative. However, adult day care is <u>not</u> a replacement for institutional care and was never intended to be -- instead it is designed to provide an alternative to nursing home care for certain, carefully selected patients.[16] In addition, adult day care may be viewed as a transitional service -- even if the transition goes on for years before the patient dies or goes into an institution. Adult day care may also help to prepare the family for a future institutionalization, should that become necessary.

But when all is said and done -- when we've looked at statistics, regulations, financing, and delivery systems -- it is still the caregivers themselves who provide us with the best and most articulate reasons to support respite services.

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Item 4

August 31, 1988

United States Senate
Office of Senator John Melcher
Special Committee on Aging
Senate Office Building
Washington, D. C. 20510

It is a pleasure to have the opportunity to supply you and Senator Grassley with a bit more detail on a few of the families in our adult day health care center. Five families were chosen to further illustrate the cost of day care, sources of payment and to compare these costs to the cost of an intermediate care nursing home bed in the Northern Virginia area.

Each of these older people is limited mentally and/or physically to the degree that they would be qualified to receive state medicaid funds for intermediate care in a nursing home. Yet in each case, the spouse or child of this person has chosen to care for them at home and to send them to day care during the day.

1. Mrs. A. a 75 year old woman who is memory impaired and confused lives with her only daughter and her son-in-law. Both caregivers work full time. Mrs. A cannot be left home alone safely, so day care provides the care she requires while they work.
   Mrs. A is ambulatory but losing bladder control.

2. Unfortunately, Mr. B. suffered 2 strokes in his sixties. He is now 75 years old, very weak on one side but able to walk. His left arm is useless to him and his speech is severely limited. His wife helps him with bathing, dressing and many other activities. They live alone in their own home and although they love each other very much, Mrs. B. finds constant care of Mr. B. mentally and physically exhausting.

   Without the care provided by the day care center during the day, Mrs. B. says she might have to consider nursing home placement. She fears that might eventually "make her a pauper" and create a sad situation emotionally for herself and her husband.

3. Mrs. C. lives with her daughter, son-in-law, and her teenage grandson. She is frail in several ways, has some chronic illnesses and exhibits obsessive/compulsive behaviors. Although she has fallen several times, fracturing bones, she can still walk and comes to the center 5 days a week on our bus. This allows her daughter to run a child care business in her home and care for her mother nights and weekends.

4. Although wheelchair-bound, mentally confused, and incontinent, Mrs. D. who is 96 years old, still lives with her son and daughter in law. Her income is very low and medicaid could have paid for her care in a nursing home for years if not for a combination of family caregiving and day care.

5. Mr. E. is only 68 years old but suffered a large stroke 5 years ago leaving him paralyzed on his left side. His judgment is not always on target but he is very alert and oriented. He says he would "rather be dead than in a nursing home" and he realizes he would be on medicaid and his wife would be "broke."

   Instead, he hires a companion to care for him at home 2 days a week, comes to the center 3 days a week, and his wife cares for him weekends, on her days off. He is wheeled in his chair up the wheelchair lift of the center bus, is assisted by the staff at the center with personal needs and is given medications, therapy, and health care monitoring by the nurse.

REIMBURSEMENT FOR DAY CARE SERVICE

	Monthly Inc.	Family Payment	Fairfax Co.	Title XX	Total Fee
Mrs. A.	1026	17	9	0	= 26
Mr. B.	1440	26	0	0	= 26
Mrs. C.	1070	31	0	0	= 26 +5/day for bus
Mrs. D.	450	0	0	26	= 26
Mr. E.	710 after other health care expense	10.50	20.50	0	= 26 +5/day bus

Nationally, the daily fee for day care ranges between $20-$50/day. The higher range becomes necessary when a center is privately run and is not supplemented by local tax dollars as we are here in Fairfax County. Our actual cost to care for each participant is $38/day in 1988, but we do not have to pay rent or utilities.

The Title XX program has an option to reimburse for adult day care. The decision rests with each locale as to whether they will co-pay along with some federal funds so that program varies quite a bit.

Lastly, to compare the cost of day care to nursing home care, one must look at that difference in each geographic area. Nursing home costs are high in the Northern Virginia area, as they often seem to be in more urbanized areas.

The base rate for an intermediate care nursing home bed in this area is approximately $75-$82 per day or $27,000 to $30,000 annually. For the private pay resident there are often many "add-on" charges for extra supplies, such as adult diapers, or extra tasks, such as hand-feeding.

Medicaid also reimburses nursing homes for eligible intermediate care residents. The rate is individual and cost-based, but an approximate range in this area is $65-$75 per day. Of course nursing homes must be reimbursed 365 days a year. On the other hand, if a person can stay at home using 5 day a week day care service, reimbursement is needed for only about 256 days per year.

I hope these case examples and these figures shed some more light on the costs and reasons for day care as opposed to nursing home care. Please thank Senator Grassley, Senator Melcher and the other members of the Committee on Aging for their support.

Sincerely,

Kay Larmer

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